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7	ALASKA HEALTH CARE COMMISSION
8	THURSDAY, AUGUST 16, 2012
9	8:00 A.M.
10	PROVIDENCE ALASKA MEDICAL CENTER
11	WEST AUDITORIUM
12	3200 PROVIDENCE DRIVE
13	ANCHORAGE, ALASKA
14	VOLUME 1 OF 2
15	PAGES 1 THROUGH 231
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PROCEEDINGS

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(On record)

CHAIR HURLBURT: We'll have a full day and a full meeting today and tomorrow. I think you will find it very interesting, stimulating, challenging, educational, and enjoyable, and we appreciate everybody being here. We -- as we normally do, we'll start out with introductions, starting with the Commission members and then we'll ask folks in the audience that have come here from the public to introduce yourselves as well. Emily, could we start with you?

COMMISSIONER ENNIS: Good morning, Emily Ennis, and I'm representing the Alaska Mental Health Trust.

COMMISSIONER MORGAN: Dave Morgan, representing primary care centers.

COMMISSIONER STINSON: Larry Stinson, a physician.

COMMISSIONER KELLER: Wes Keller, representing the State House.

COMMISSIONER CAMPBELL: Keith Campbell. I live in Seward, and I'm the consumer rep on this commission.

COMMISSIONER ERICKSON: Deb Erickson with the Health Care Commission.

COMMISSIONER BRANCO: Pat Branco with the Alaska State Hospital and Nursing Home Association.

COMMISSIONER HIPPLER: Allen Hippler with Alaska State

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COMMISSIONER URATA: Bob Urata, a family physician from Juneau, Alaska representing primary care physicians.

COMMISSIONER HARRELL: So I'm Tom Harrell. I'm a cardiologist. I'm the Commander at the Joint Base Elmendorf/Richardson Hospital.

CHAIR HURLBURT: And I'm Ward Hurlburt. I'm the Chief Medical Officer and Director of Division of Public Health with the State and the Chair for the Commission.

I'd like to recognize Senator Bettye Davis and express our appreciation for your coming and joining us. You and Tom have both been very faithful and very interested right along. So Tom, could you go ahead and introduce yourself? And then we'll go around the room.

TOM (LAST NAME UNKNOWN): (Indiscernible - away from mic)

(Audience introductions indiscernible - away from mic)

CHAIR HURLBURT: Welcome to everybody again. Thank you for coming.

The focus for our meeting is End-of-Life Care. As with everything else we talk about, it has clear financial implications. We spend 1% to 2% of our gross domestic product on End-of-Life Care, and we see a whole wide spectrum. Those of us who are physicians and probably almost everybody in the room has beautiful, wonderful stories about end-of-life and transitioning for individuals and for families. Probably all

of us in this room, physicians, and again, most of the others of us here, have stories that are not so happy of times of suffering, of anger, of being unhappy with what has happened. Those of us who are scientists, and most of us in the room are, in one way or another, have stories of some of the miraculous things that can be done by our health care system through the knowledge that we have, through the technical capabilities that we have. The things at the beginning of my career as a physician would be undreamed of and are, clearly, miracles. All of us have stories about some of those capabilities prolonging dying, inflicting harm, inflicting suffering.

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And so we have a wide spectrum here that we're going to talk about, something that impacts every one of us, every one of our families, every one of our friends. The mortality rate remains 100%, sooner or later, and it's a fact that we have.

We are particularly privileged today to have Dr.

Christine Ritchie join with us here, and she will be leading our discussion, will be sharing some information and perspectives and experiences with us. And then we will have two Reactor Panels, that many of you in the room who have introduced yourselves will be participating on, for the balance of the morning here.

Dr. Ritchie is a board certified geriatrician and palliative care physician. She currently is Professor in

Residence at UCSF in San Francisco, the Division of Geriatrics and was recently appointed the first recipient of the Harris Fishbon Distinguished Professorship in Clinical Translational Research in Aging.

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She leads the development of a research program there at UCSF to improve the care and quality of life of older adults. She graduated from University of North Carolina in Chapel Hill, completed her training in internal medicine and a fellowship in geriatric medicine at University of Alabama and also achieved a Master of Science in Public Health.

She moved to the West Coast just about five months ago from the University of Alabama where she had been Professor of Medicine and the Director of the Center for Palliative and Supportive Care, the Director of the Palliative and Supportive Care Section, Director of their Foundation for Comprehensive Program to Improve Geriatric Care. She's done research that's focused on advanced illnesses, multi-morbidities, care transitions, supportive care in cancer and other serious illnesses, informatics, emerging technology, and chronic disease management, geriatric nutrition, oral health and systemic disease, and education research.

I think we all owe a real debt of gratitude to Deb for reaching out and finding Dr. Ritchie because, from what I've just said, it's clear we are truly honored and appreciate your coming to share with us, Dr. Ritchie. So I'll turn it over to

you.

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2 (Pause)

CHAIR HURLBURT: We do transcribe all of our meetings and so we need to get it into the mic to do that.

DR. RITCHIE: Can you hear me now? Very good. Well, I feel like it's a tremendous privilege to be here, and I've always had a very strange sense of connection to Alaska, one, because I've lived in Alabama for quite a few years, and whenever you put your state of residence down, you can easily, mistakenly put Alaska instead of Alabama. Second of all, I grew up in South Korea, and you know, way back when, the Bering Strait actually connected that part of the world and this part of the world. So I've always had a sort of sense of connection to Alaska. So it's really a delight to be here.

What I'd like to do today is, hopefully, just set the stage for a conversation because there is so much to say and so much to talk about that this really is just to sort of provide a context and to make sure we all sort of maybe have some of the same information. Then I hope really what's -- what really happens and what will, hopefully, enrich all of us is the conversation and the dialogue that ensues after this first presentation.

So first of all, I want to talk about Chronic Serious

Illness. You've heard the word used, End-of-Life Care,

Terminal Care, and certainly, that is part of our reality. We

do currently have, for most of us, 100% rates for mortality, ultimately, in our life, but what is a new reality actually is that we are doing a worse job than ever for good reasons in actually figuring out when people are at the end of their lives, and part of that is because technology is helping us do well, or at least, live -- maybe not well, but live longer.

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And so I really want to talk about the challenge of chronic serious illness and reframe some of our discussion about End-of-Life and Terminal Care within that context and then talk about the value equation, which is, how do we deal with quality and cost in this new reality of chronic serious illness? Our health care systems were not developed to deal with chronic serious illness.

And then what I hope will really be a point of discussion for us, as a group, is, how do we improve systems of care through the integration of palliative care, among other things, because palliative care is not the only answer. It's part of the answer, and Alaska offers some very interesting opportunities to do good integration of palliative care, almost like no other place in the United States and that is very exciting.

So first of all, part of the reality of chronic serious illness is that we all are having the opportunity to live longer, which, as a general matter, is a good thing. This is a -- let's see if my little mouse -- oh, there; it does work.

So this is a figure from a paper that came out in *Nature* a few years back that was looking at global aging, and what's really remarkable is that what this shows is that very soon many, many countries in the world, including the United States — although, we actually are lagging behind many of our sister countries elsewhere — will have over 30% of their population of the age of 60 and that really changes our reality for a number of reasons, but this is a new phenomenon that's never occurred in human history, and it does have meaningful implications for how we think about provision of good care.

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And not only is this proportion of the population changing, but the median age of the population is changing so that, if you think about it, all -- if you look at anybody across the age spectrum, as we move down sort of the timeline, that age is also increasing. So what it looks like is like a snake that's eaten a rat, and what that means is that, you know, in the past, what we saw was that there were more, generally speaking, people who were younger than older. Now essentially, that snake is moving down the path, and you see, pretty much all along the age spectrum, about the same number of people, and the implications for that mean that (a) we have fewer caregivers, (b) we have, potentially, a change in our ratio of workers to nonworkers or people who can provide care versus those who need care. This really changes the dynamic of what we have to contend with and really offers us some good

opportunities to think creatively.

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In addition to this aging issue that we're seeing, we're also seeing this chronic -- what I call the Crisis of Chronic Illness. So technology, public health, they have actually impacted in such a way that we are living longer. That's very exciting, and there is a large (indiscernible - recording interference) of people who are living longer well.

So if you look at actual rates of disability, the rates of disability are not going up at the same rate that the rates of aging are going up, which is a good thing, but if you look at the absolute numbers and then you look at some of the challenges that we're facing as a society that relate to obesity, diabetes, hypertension, and other behavioral health-related phenomena, this issue of chronic illness is now going across the age spectrum and having very meaningful impact for how we're going to deal with it as a health care community.

So what does this mean then? It means that you are more likely to have a chronic condition. You're also more likely to live longer. You're more likely to collect chronic conditions as you get older. And so by the time you're 85, you're pretty lucky if you don't -- if you haven't collected, at least, one or two chronic conditions, and actually, 20% of all people over the age of 65 have four or more chronic conditions.

So what this means is that we have a Crisis of Aging -- I

mean, it's not a Crisis of Aging. Aging is a good thing. We have global aging, a Crisis of Chronic Illness, and coming along with that now is we're having chronic serious illness, and again, this is something that is generally positive. People who used to have serious illness died, often immediately.

Now people are living longer with advanced serious illness, and what that means is that they have high illness, often, in symptom burden, and the management complexity becomes quite meaningful. That relates to patients, how they manage multiple conditions that they're contending with. It's not just cancer anymore. It's cancer and heart failure and chronic obstructive pulmonary disease and diabetes all at once. It's a financial stressor, often, for not only the person who has those conditions, but their family members and their caregivers. People are dealing with multiple providers who are, often, telling them different things about what they should be doing.

What it means for those of us who are providing care is that we have to be clued into the fact that, for patients who are dealing with this, their goals and preferences will be dynamic and will be contextual. It will be based on what is going on in their life at that time with the conditions that they are experiencing at that time. And an area that, unfortunately, we have very little research to guide us is

these conflicting and interactive treatment regimens because, as most of you know, when we do clinical trials, we actually exclude all the people who have multiple medical conditions or who are older and so those people are not informing a lot of the information that we are providing to patients that relate to specific treatments.

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So what are some examples of this serious chronic illness? I think most people would venture to say that, if you are on dialysis, that's a serious chronic illness because, if you go off dialysis -- not uniformly, but many people will die if they go off of dialysis.

What's interesting now is that the largest number of people who are going on dialysis are actually those over the age of 65. They're also the largest population who are experiencing kidney failure. So that, in 2008, there were, you know -- and by now, there are close to 100,000 adults 75 years and older who are receiving dialysis. Most of those older adults don't just have that one condition. They have multiple conditions that they're facing and that means that their caregivers and everybody else, including the care system, are having to deal with that particular serious illness and many others.

Cancer. We used to think of cancer as one of those things that you either were cured from or you died, and actually, that's not true anymore. What we're being able to

do now with a lot of our chemotherapeutic agents is actually help people live longer with serious cancer.

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When I was in training and I saw someone with advanced ovarian cancer, I, pretty much, assumed that I wouldn't see them for very long. I've now cared for people with advanced ovarian cancer for two to three years. Pancreatic cancer, one to two years. These are very sick people. These are people who are actually dealing with a lot of issues, especially with respect to symptom burden, for a long time.

And in terms of the incidents of care, the incidents of cancer, pretty much, follows with aging. So as we see growth in our number of older adults, we're going to see the growth in cancer incidents, and cancer, as a chronic serious illness, is going to grow substantially in the coming years.

Same with heart failure. The good news about heart failure is we've learned to manage it better, but what it means is that -- and so our one-year, risk-adjusted mortality rate for heart failure actually has declined, but what that means is that, if you have advanced heart failure -- and most people, as you -- have you met anybody with advanced heart failure who is not on, at least, five medications? It's very unusual and that's just for their heart failure. Those individuals are living with serious illness for a very long time, and there still is a relatively high one-year mortality rate for those individuals, but they still are having to deal

with serious illness for a long time.

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So what I want to point out, and hopefully, have been able to communicate to you, is that, when we think about End-of-Life Care and we think about Terminal Care, it is not a linear phenomenon, and it is not an easily predictable phenomenon. And so as we think about providing good care for people who have serious or terminal illness, we have to recognize that, many times, we don't know who those people are just by seeing what their "life expectancy" is because life --our ability to prognosticate in a grandeur way is not great, and it's actually becoming less great because our technology is helping people live longer, but not a lot longer, and there are lots of burdens associated with the technology that we're offering.

Again, to highlight the fact that our disease trajectories tend to not be linear is that, when you think about someone when they are diagnosed with a condition, they may have times when their illness burden is high and when their illness burden is low and that will, often, go like this. Any of you who have actually cared for somebody who has heart failure or cancer or advanced dementia, know that it tends not to be this sort of predictable phenomenon. It's all over the map, and it's getting more that way because people aren't coming in with just one condition.

What that means is, when we think about good care for

people who have serious illness, we really have to be thinking about addressing good quality care to address quality of life and make sure that preferences are aligned across their illness trajectory.

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So I just wanted to sort of make sure we were still all on the same page about what serious illness looks like and then talk about what this means for us in terms of quality and cost, and many of you, probably, are familiar with the whole idea of valuation equation. It's been thrown around in public policy circles a whole lot lately by everybody, and it's a reasonable thing to think about, which is that, when we think about care, we want to provide the very highest quality of care at the most reasonable cost. If we're providing poor quality care at high cost, something is wrong and that's an opportunity for us to actually find solutions and do something about it.

So let's look at our numerator quality in the United States. Many of you are familiar with the 100,000 deaths initiative -- actually, some studies suggest that it's actually a real underestimate in terms of what we do. It may be more, like, 185,000 deaths per year that we contribute to by virtue of medical mismanagement. I think errors is probably too strong of a term because, really, it's because our systems are so poorly connected and aligned that a lot of these things happen. You know, it's the Swiss cheese

phenomenon, which is every one person is trying to do the best they can, but if somehow all those Swiss cheeses come together and there is a whole there, the bullet can get through and that's what we see a lot in the United States' health care system. The harm occurs all along the spectrum. So many people are not getting enough care or adequate care. Many people are getting too much care, care that's actually harmful to them, and then in some instances, they're just getting the wrong care.

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Fragmentation is all of our realities. How many of you have had to navigate the health care system recently for a loved one? Can one of you just say what that was like?

Anybody? Yeah?

UNIDENTIFIED FEMALE: (Indiscernible - away from mic.) I had to take my mom to multiple appointments over a large geographic area, and you don't get the same answer from the person. So it was really tough and then the quality of care isn't there. She's having pain issues, and her health status doesn't improve, and she's either having impact from not solving the pain or not being coherent because of the medications.

DR. RITCHIE: Thanks, and I'm sure almost all of us could probably describe something similar, and what's remarkable, to me, is, when I get a bunch of physicians together -- so you would expect physicians to, generally, have a good handle on

the health care system and be able to serve as relatively good advocates for their loved ones -- they struggle. Maybe not to the same degree, but they struggle a good bit as well. So fragmentation is an issue that we all struggle with and suffer from.

And what's particularly discouraging, I think, is that we also don't know how to get evidence-based medicine actually into our lives. If you're a provider, you know that it's impossible to keep up with the literature, as much as you might want, that there is a lot of controversy about what particular data is telling you, but even on the data that's abundantly clear, we don't have systems in place to help people actually do evidence-based care, where it's pretty obvious, for example, that it would be useful for someone to be put on aspirin after they've had a heart attack, that that still happens a lot of the -- that still does not happen a lot of the time when people leave the hospital.

And then when you look quality indicators that relate to health care quality, especially life expectancy and access and patient-centeredness, we don't do quite so well, and I think most of us who are in the United States want to think that, you know, we're pretty much the best at everything, or at least, most things and so to be 40th -- and it varies, you know, between 35th and 45th, depending on which quality indicators you look at -- somehow, it doesn't feel so good, to

me anyway. And then when we look at, actually, what patients tell us and what caregivers tell us, we also see that we're actually falling short in terms of quality.

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So with patients who have serious illness tell us is that they want their symptoms managed. They don't want inappropriate prolongation of the dying process. They want to live as long as they can. I don't know many people who don't want to live as long as they can. Most of us have a very strong survival instinct, but we don't want to be dying over a long period of time and to have our dying process prolonged in such a way that it causes us suffering and the ones we love suffering.

Most patients want some level of control. They don't want to be a burden on their family, and they want the end of their lives to be characterized by strengthening of relationships, not disintegration of relationships. They want to actually have trust and confidence in their providers.

They don't want to be kept alive if there is little hope for recovery, and they want communication, and this, to me, actually when I talk to providers and to consumer groups, is one of the key things is let's really understand what's going on here, recognizing that none of us have a crystal ball and we can't figure out everything, but having as much information as possible. They also want to be able to complete things and be prepared. They don't want to have unclear plans when they

live the hospital, and again, this is a different study by

Darrin Highland and his group. They want to have complete -
or at least as much as possible, relief of their symptoms.

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What about caregivers? They want their loved ones' wishes honored. They prefer to be involved in decision processes and that, often, varies by culture and a particular family style. They want help and that help, often, does not translate when people live the hospital. They often feel abandoned when patients leave the hospital. They want to have somebody to talk to in the middle of the night, and they want to be listened to and have some, also, dignity and preservation of privacy.

Family members do appreciate being contacted after death and being able to give their side of the story, both as a way of maintaining a legacy for their loved ones and also to be able to provide feedback that may help improve our systems.

What they get is not exactly what they want. So this is a study by Joan Tino (ph), but there are many others that have shown, pretty much, the same thing, which is that, when you talk to a lot of people who are family members of people who have recently passed away, they generally say they didn't get enough contact with the physician. They didn't get enough emotional support or information about the dying process and that, in many instances, they didn't get adequate symptom management support.

This was a study of folks from four ICUs, including the VA, but not just the VA, looking at families' perception of dying in the Intensive Care Unit, and again, unfortunately, more often than not, pain was not under control. Dignity and self-respect were not maintained, and people did not die breathing comfortably.

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So this is, often, what we sort of ask of our patients, right, which is we sort of just want them to suffer in silence. This is just the way it is, and you know, stay tuned; maybe things will get better. But I think everybody is here in this room because you don't want that, and you don't want that for your loved one, and you don't want it for your patients, and we all want to have health care systems that will help us move in the right direction.

This is a nice quote from Ira Byock's The Best Care. I don't know, have any of you had a chance to read that book? So you all have received it. So if you can add it to your reading list, it's a very nice sort of overview of, really, some of the issues that we're discussing right now and that are being faced in our society. And I think Ira says it very nicely here, which is that, "for people whose diseases will not be cured, but instead progress, despite aggressive treatments, the very places that are meant to provide the best care can become (indiscernible - voice lowered) of discomfort, false promises, and foreboding," and I think most of us don't

want that for our -- in the places where we work, and we don't want that for the people for whom we're caring. So that's quality.

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Let's talk about cost. This is now becoming a real issue for most businesses in the United States. Businesses are increasingly saying, well, if the health care system can't figure this out, we're going to figure this out because we cannot continue to pay higher premiums for our workers.

And again, we are unusual in the percent of our GDP that we spend on health care, and even despite that, there are a whole bunch of people who actually don't have health insurance and who probably have inadequate access to care.

In the brief that I read about Alaska health care, Alaska sounds like you are up with everybody in terms of people who are either uninsured or underinsured and that lack of health care coverage, at least based on a recent study that came out of Harvard, may contribute to, at least, in the entire country, 45,000 preventable deaths per year. So we have high cost, and yet, our support for patients in our society is not consistent.

This is based on showing something you all know, but sometimes it's helpful to just see a visual representation of what's going on with our health care cost as it relates to our GDP. And here we sit, a lone ranger, and all the other countries in terms of our health care spending, and there are

a lot of reasons for that, and actually, we don't quite understand all the reasons for that, but we have some ideas about some.

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Part of it does relate to the fact that we have this epidemic of chronic serious illness and multi-morbidity, and we certainly do observe that the individuals who have the highest number of conditions are the most likely to be the most costly, but not only that, it appears that about 5% of Medicare beneficiaries do account for 50% of Medicare spending, and it's not just related to comorbidities. There are other complexities that both relate to the way we provide care and the way people are living in terms of their social contexts that are contributing to high health care costs in the United States.

This impact is not only on the GDP. It's not only impacting our businesses, but it actually impacts personal expenditures, so that more and more people are -- and I'm sure many of you may have experienced this personally -- I certainly have, moving to California -- is that the health care out-of-pocket costs for everybody are increasing, and unfortunately, thousands of foreclosures in the United States and a large percentage of bankruptcies in the United States are attributed to, basically, financial devastation related to health care.

I have seen many patients in my supportive care practice

who were well-functioning, working citizens who, when they became sick, lost their health insurance. It takes almost an act of Congress to get disability insurance or any kind of supplemental insurance in the state of Alabama and so what happened is these individuals lost their jobs, lost their health insurance, and now are dealing with a serious illness and were, pretty much, relying on whomever they could, churches, friends, you know, any agency that they could run across to help them, if they could, manage and navigate through their serious illness, if they were going to live long enough to be able to even receive care.

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So with that backdrop then, how might palliative care contribute to the Value Equation in chronic serious illness?

Well, first of all, what is palliative care? I had the good fortune of sitting next to somebody who actually is related to the Providence Health Care System nationally on the plane yesterday, and we talked the entire time about what palliative care is and is not.

Many people in the United States think of palliative care as being synonymous to hospice care. And hospice is a very important benefit in the United States for people who have a life-limiting illness where we have a good idea about what their prognosis is, but hospice is, in my estimation, pretty much an insurance benefit, and it has a lot of restrictions as a result that have nothing to do with necessarily the care

1	that's received in hospice, but actually does affect the care
2	that's received in hospice. It's a capitated benefit. So
3	hospices, generally, get \$100 to \$110 per day to provide
4	support for patients who have serious advanced, life-limiting
5	illness, and if that is the case, many times, if they need any
6	kind of treatment that is very expensive, they're not going to
7	be able to stay on hospice.
8	So hospice in the United States, which is different than
9	in other parts of the world, is really, in many people's
10	minds, associated yes?
11	COMMISSIONER URATA: I'm sorry to interrupt you, but
12	DR. RITCHIE: Please.
13	COMMISSIONER URATA:I think what you're speaking of
14	is the hospice Medicare benefit
15	DR. RITCHIE: Thank you.
16	COMMISSIONER URATA:as to the insurance company.
17	Hospice is palliative care at the end of life
18	DR. RITCHIE: Thank you.
19	COMMISSIONER URATA:and I want to make sure people
20	have that clear.
21	DR. RITCHIE: Thank you. That's a very important point.
22	So hospice, as many people know it, is the Medicare is a
23	Medicare benefit that has very strict criteria. Hospice, as a
24	general matter and really, palliative care really grew up
25	from hospice is focusing on improving quality of life,

improving holistic care for people who have serious terminal illness.

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So the reason I want to bring that up is because, although hospice is a very important element of palliative care, palliative care has some advantages in that it can, basically, take hospice and move it upstream. It can offer all the good things of hospice, but at least in the case of Medicare, not be restricted by some of the sort of issues that we deal with because it's used as an insurance benefit.

This actually comes from the Medicare Hospice Conditions of Participation, and the definition there is that palliative care means "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering." It occurs throughout the continuum of care and is really focused on addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information, and choice.

The difference between palliative care and hospice, from the standpoint of Medicare, is that palliative care does not require knowledge of prognosis, or at least, that we think the person has six months or less to live. That's actually very liberating because we often don't know if people have six months or less to live, and what that means is that we can again apply then many of the standards, many of the philosophies of hospice that are important to improving

quality of care and offer it then to people across the continuum of care who have serious illness, when we don't know whether or not they're going to live six months or whether or not they're going to live two years or whether or not they're going to live five years.

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Palliative care and hospice both focus on a team-based approach. In fact, you can't do palliative care or hospice without a team. It requires having a complement of people who have different areas of expertise and that actually use those areas of expertise in a coordinated fashion to optimize quality of life and quality of care for the patient and their caregivers and their loved ones.

This is an actual conceptual shift, and part of the reason I provided this dichotomy earlier between hospice and palliative care is that the Medicare hospice benefit -- and is it Robert? Rob. Thank you, Rob, for clarifying that. The Medicare hospice benefit is very much restricted to having a life expectancy of six months or less. So if you're a physician and you actually want to offer hospice to somebody, you actually have to sign a form that says, I do not think this person is going to live longer than six months.

Now we all know that, because we all do such a bad job with prognostication, there are going to be people who actually will live longer than six months, and nobody goes to jail if that happens, but it is an issue that often keeps

people from going into receiving the kind of services that hospice offers because of this sort of event. And then also what often happens is that, historically, in health care, patients and their loved ones felt like this is what would happen. You know, so intense, aggressive cure would occur, and then suddenly, someone would say to them, there is nothing more we can do for you; we're actually sending you to hospice.

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So from the patient's perspective, it felt like they were thrown over a brick wall, abandoned by all the people who knew them and the entire care team that supported them to a whole different care team that had no connection with the previous care team, and this is, I think, what's led to some disconnect in the United States, especially with hospice and the rest of our health care.

And so what palliative care is trying to sort of emphasize is, yes, hospice care is appropriate for many people who have serious terminal illness, but palliative care is appropriate, really, for anybody who has a serious illness and has illness burden that can benefit from a whole person approach to addressing quality of life.

And so palliative care should be considered at diagnosis of any serious illness. If I come to the hospital with a massive heart attack and end up with an ejection fraction of 25%, I have suddenly developed a serious illness. If I'm diagnosed with Stage IIIC lung cancer, I have a serious

illness. If I have been diagnosed with Lewy Body Dementia, I have just gotten a serious illness, and at that point, I should be given the opportunity to, at least, have access to people who can talk to me about illness burden, quality of life, legacy, what does this mean, how can I make sure that my preferences about what's important to me are translated into the care that I receive, and again, remembering that palliative care is a dynamic, not linear, phenomenon, and it should be offered in a dynamic, not linear, phenomenon.

So here, you can see that, when it's clear that actually someone's life is really advanced and that we have some sense that they truly are in the last months of their life, it's a very good idea to offer them hospice because they will receive a kind of coordinated benefit that can be extremely helpful for them and their loved ones, but there are going to be many other times during their illness journey when they will need supportive care services and that's really where palliative care can be helpful because those supportive care services are really about aligning patient preferences with the kind of services and treatment that are being considered at the time.

There have now been a number of studies that have looked at palliative care and its impact on a number of different quality indicators. This is the Mortality Followback Survey that looked at palliative care versus usual care, and essentially, found that, in the instances of the items that

were measured -- emotional and spiritual support, information, communication, care, time of death -- palliative care was superior. Was it always superior? No, but in many instances -- and well, in the large majority of cases, it was superior, and I think one of the things that's particularly intriguing, to me -- and many of you may be familiar with this as well -- is that there is a trauma that occurs, often, to the caregivers and loved ones when they go through this illness progress with someone that they love, and we're seeing a lot, actually, in the Intensive Care Unit.

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You know, in the Intensive Care Unit, people -- loved ones are often disconnected, alienated, isolated from their loved one and then they see their loved one actually often undergoing significant amounts of suffering and feel completely helpless and unable to control the situation. And now actually, there have been increasing number of studies coming out that show that there is a kind of Post-Traumatic Stress Disorder that occurs in a subset of caregivers who have actually watched their loved one in the Intensive Care Unit, and especially if that loved one died in the Intensive Care Unit. So what palliative care seems to be able to do is to help mitigate that and to help actually minimize some of this trauma and stress associated with experiencing serious illness in our health care system.

In another study of 332 cancer patients, when they asked

whether or not they had had a prognostic goals of care conversation, those who actually had had somebody talk to them and say, what's important to you; given where you are in your current illness journey, what are the things that you want and don't want to have happen to you, that those individuals generally had better quality of dying, a lower risk of complicated grief, interestingly, lower costs, and also less aggressive care, which suggests, to me, that really what we're dealing with here is that there is still, in the United States, sort of a misalignment between what our patients want and what they receive, and a lot of it probably just has to do with we, as providers, don't understand what people want, and we're not necessarily giving people enough information to get the information that they need to make the decisions.

2.2

I, certainly, have engaged in -- and I'm sure many of you may have experienced this as well -- what I will call default medicine. That is, we do stuff because we saw our attending physician when we were a resident do it, and we make a lot of decisions about treatment that aren't necessarily based on data or information or the person who is sitting in front of us, and a lot of times, that default medicine can be harmful and costly and not necessarily be aligned with what people actually want when we ask them what they want.

This is actually a study at a hospice and palliative care initiative that was put forward by Aetna where they,

essentially, expanded hospice-like services to people who weren't hospice eligible by the Medicare benefit criteria, and what they found is that those individuals actually ended up using hospice more often, they had lower emergency room visits, and lower acute inpatient admissions when they actually were offered these services, which were really a lot about communication and issues that related to improving quality of life.

2.2

How many of you saw this study by Jennifer Temel or heard about this study? A few of you. Great. So this is an interesting study that looked at early palliative care for people with metastatic non-small cell lung cancer. So lung cancer, especially if it's diagnosed in the advanced phases, generally has a very, very poor prognosis, but in the sort of mid-stages, the prognosis is poor, but not as poor as if someone has Stage IV, and those people who were sort of in the mid-stages tended not actually to be thought about as having, necessarily, a terminal illness. They tend to get a lot of treatment, chemotherapy, radiation therapy, that sort of thing, and when it's abundantly clear that they have a Stage IV illness, then they are considered for more sort of palliative care interventions.

So this is a study actually done out of Harvard at Dana-Farber, and what they looked at is early palliative care. So what they did is they identified people who had Stage IIIC lung cancer, and anybody at the point of diagnosis was given the opportunity -- or were actually randomized to get palliative care then versus palliative care sometime, maybe never, maybe, you know, depending on what their doctor preferred. Obviously, the people who participated in the study had to be agreeable to actually doing this, being a part of this study, as did their providers.

2.2

What was interesting is that people who received early palliative care -- and this was a team-based -- remember, it's a team-based approach that's really focused on addressing sort of psychosocial, emotional, physical illness-related burdens -- that they had lower levels of depression, lower levels of anxiety, and lower levels of major depressive disorder, and as a palliative care physician, I would say, well, I hope so because that's really what the treatment is supposed to do.

What was interesting about this particular study is that, actually, the people who received early palliative care lived several months longer than those who received regular care.

Now remember, many of those people who had standard care did, ultimately, receive palliative care services. The issue here is when, right? And we don't really know why those people lived longer, but what I would hope is that part of the reason they lived longer is they got what I would call patientaligned care, that their preferences were driving what was actually happening to them, and they weren't necessarily

getting treatment that may have been, ultimately, more toxic and less beneficial, especially if it wasn't inline with what they wanted.

2.2

The reason this was a useful study for, I think, the health care community is because there has often been a sort of sense that, if you get hospice or you get palliative care, people have "given up" on you, and you know, we've washed our hands and that, generally, your survival will be lower. And what we seem to be seeing is actually that's not the case, that survival does not seem to be reduced with receipt of these kind of services.

So given that sort of understanding of palliative care and of hospice, then how could palliative care potentially support patient-centered care across the continuum? And I'm just going to put forward a couple of -- a few ideas. I really hope this can be a time where we can generate discussion about ideas that are particularly relevant to the state of Alaska and to the communities that are served here.

So first of all, a provider focus, which is that, in the state of Alaska, I think Dr. Rust has told me now that you have four to five palliative care physicians in the entire state. That's not going to be adequate to be able to provide good access for palliative care, if you're expecting everybody to get specialized palliative care services. But on the other hand, if basic palliative care skills are provided to all

primary care providers, to mid-level providers, to the community health aides in various, you know, remote communities and some level of education is offered, this really could be a wonderful place to demonstrated how a systematic system of education and referrals can actually improve access to a large number of people who are seriously ill.

2.2

Then there is whole opportunity of systems focus. I'll talk about triggers and care transitions and then integration of technology focus, which is an area of particular interest to me, but again, don't want to sort of dominate the conversation on that, but I think it's, again, an opportunity here in Alaska.

So what would be some basic palliative care skills?

Well, I think basic palliative care skills fall under what we have historically called Advanced Care Planning. I actually don't like the words Advanced Care Planning because, often, it's sort of thought of a static phenomenon. You know, you fill out your Advanced Directive, and then, you know, whatever it says, you're kind of stuck with. That's not the way most of us want to live. You know, we want our decisions to be contextually based on what's happening to us and to our loved one at the time. So I would really call this, instead, Developing Skills in Dignity-Driven Decision-Making or Patient-Centered Decision-Making, where the actual question is

asked, what do you care about? What are your goals? How can we make sure the treatments we're offering are actually matched to those? And how do we make sure that whatever you really want we actually deliver on, because we're kind of bad at that? You know, people will say, I want you to do everything possible to support my living as long as possible. They don't get it. And then people who say, I really do not want to have this level of burden related to treatment. So when it comes to that, please do not provide it. And many of you will have stories from your own families where that happened, right? So it's really about actually helping providers engage in some very basic skill training related to communication about decisions and how can we make sure that we get what people's values are, so that our treatments are aligned with their preferences.

2.2

And then a related topic is communication in terms of giving bad news. One way that we actually sort of create a disservice to patients is that we don't tell them when they're actually sick, and you'll have patients and caregivers tell you, no one told me he was this sick. If I had known, you know, my husband was this sick, I would not have been here; I would have been home. We would have been sitting on the back porch, you know, looking at the sunset together. And so there is this disconnect between actually our communication and what often people want to know.

Well, there is a reason for that. I don't know about you, but most people, including myself, we don't really like telling people bad news. So we have to give people skills on how to tell bad news in an empathic way and in a way that actually addresses and brings in a team that can address social, spiritual, existential concerns.

2.2

And then symptom issues. You know, we talked earlier about part of our challenge with health care quality is that we're not managing people's symptoms well, and this is not easy. Anybody who has dealt with pain management, especially chronic pain management, knows this is not easy. Your mother, you know, trying to manage her side effects from her treatments for her symptoms versus her actual symptoms, this is a challenging thing, but there are some sort of initial tools that can be used that can be very helpful here. And then if it's actually not basic, then to feel comfortable with then sending people to people who have additional training.

What Dr. Rust has told me is that, in addition to the five physicians who are trained and certified in palliative care, there are also a number of other people who are midlevel providers, social workers, spiritual care providers who are also certified in palliative care. That network of specialists then can be available as a referral source, but they don't have to see everybody. But for people to actually feel freed up to not feel like they have to do all this

themselves, it really is a way to improve the efficiency of our system. You know, as our trauma surgeons used to say to us, we're so glad you're here because we really don't want to have to be dealing with us; we'd rather be in the OR. And you know what? They should be in the OR. That's where they're doing the most good and that's where they have skills that the rest of us don't have. So really working collaboratively in a complementary way can be useful.

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And then there is this whole idea of co-management. Most physicians, in particular -- I'll pick on my training and my specialty and that is we grew up thinking of ourselves as free agents and independent agents, and you know, I was in charge of the -- especially if I'm a primary care provider, I'm in charge of this patient, and you know, what I decide for this patient is what should happen. Well, what we're recognizing, especially with people having such complex conditions and multiple conditions, is we can't do that anymore. We actually have to work together and sort of take pieces of the pie and say, can you help me with the symptom management part? I'll deal with the chemotherapy. Or can you help me with, you know, the rehab issues related to this person's recent hip fracture? I'll deal with, you know, supporting the family and addressing symptoms when the person gets home.

So this whole opportunity to engage in co-management actually is a little bit of a culture shift for most

physicians, I'll say, but it can be actually quite liberating when you become comfortable with that. And what I saw with my oncology colleagues at UAB is that, when they actually became comfortable with this co-management, they felt great because they knew the issues were being dealt with and they didn't have to deal with them all, but they were dealing with things that were particularly important for their skill sets. The only way this works is with high levels of communication and trust between providers. It will not work if there is not a high level of communication and trust.

2.2

Now let's talk about systems. So we talked about systems. So we talked about providers. With respect to systems, there are certain areas where there are particular gaps in palliative care delivery models here in the United States, and fortunately, in hospitals, there is a growing work that's being done with palliative care, which is a really great thing. So 75% of all hospitals that are over -- who have a census of -- average daily census of over 300 have palliative care programs, for example. And fortunately, we have hospice, which also offers a very important palliative care treatment and management opportunity for people who are, clearly, at the end of life, but in the home, in short-term rehab, not so much.

And so this is really an opportunity, I think, as you think about sort of a systems integration approach for

supporting people who have serious illness across the continuum of care in the state of Alaska, to think about how to deal with those gaps everywhere along the way. And then think about how care transitions can potentially be a place to think about palliative care being of service and that care transition can be either setting of care -- so a person's in the hospital; they go to Pioneer Home or they go to their home or they go to a nursing home. Any change in setting of care is a great place to think about considering palliative care and then also goals of care transitions, where there is some new event that's changed the playing field and new decisions need to be made. Yes?

2.2

COMMISSIONER HIPPLER: Thank you. There have been several slides that appear, to me, to indicate that palliative care should continue after death. Can you explain that again real quick?

DR. RITCHIE: Yes. Thank you for bringing that up. So this is actually, again, a tradition that originated in hospice, which is that, if you're going to do whole person care and family-oriented care, even though the patient is no longer in the picture, the family unit is still there, grappling with the loss of their loved one. So bereavement support really is an expectation of good hospice care. It's actually a requirement. But as we think about quality of care, there is an increasing recognition that bereavement care

shouldn't be just for people who are lucky enough to get hospice, that anybody who has actually been a part of a health care delivery system and who has loved ones should have the opportunity to be receiving some level of bereavement support after death. Does that answer your question?

COMMISSIONER HIPPLER: Yes.

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DR. RITCHIE: All right. So in terms of triggers for sort of a systems-based integration of palliative care, you can think about care transitions as being one trigger and then really thinking about, again, that small population of people who have the most complex chronic serious illnesses as being the people for whom palliative care is most likely to help, and they fall under a lot of different categories. So we think about cancer. Actually, this is sort of an old paradigm, cancer being one of those things where, you know, you're doing fine -- and we all know people who were playing golf one day, and then the next day, they come into their provider's clinic and they've been diagnosed with pancreatic cancer, and three months later, they're no longer with us. So there is, often, a precipitous decline with cancer, but not always.

With organ failure, it's like this. So whether it's liver failure, lung failure from chronic restrictive pulmonary disease, heart failure, it's all this sort of sawtooth pattern, where people are doing okay and then they have a bad

event, and hopefully, they survive that and then they're doing okay. Then they have a bad event. But these are the people who tend to be high health care utilizers, often high cost, often low quality of life, low quality of care, who really are most likely to benefit from this holistic team-based approach that you see, that you would be considering for palliative care.

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And I don't want to leave out dementia and frailty. You know, dementia is now becoming actually an epidemic in the United States. We'll soon be moving from having four million older adults with dementia to 16 million over the next decade, and it causes huge levels of caregiver burden. It's very difficult to know when people who have dementia and frailty are at the end of their lives, and these people and their loved ones benefit greatly from having a whole person team of providers supporting them as they go through that process.

There are a lot of triggers that you could think about from a systems-based perspective in the hospital setting. One that Joanne Lynn (ph) has often espoused is, would you be surprised if this person died in the next year? Not, will they because, again, we're not very good at that, but would you be surprised? I found this to be, actually, quite helpful, to me personally.

When my father was at the end of his life, I actually wasn't very clued in about that. He had advanced dementia,

and I actually asked myself this question when I was trying to think about when hospice services would be appropriate for him because I couldn't -- I certainly could not see whether or not we were dealing with months or years, and when I asked that question, actually, is when I actually asked for help because, otherwise, it's sometimes hard to know exactly, but if you're not -- if you wouldn't be surprised if the person died, then it's likely they have high illness burden and that their family and caregivers are dealing with that as well. Are they having symptoms that are really difficult to control? Have they been in the Intensive Care Unit for a long time?

2.2

We already talked about the Post-Traumatic Stress experienced by caregivers. If, for no other reason, actually having palliative care involved for the caregivers for someone who is in the Intensive Care Unit can be beneficial. If there is complete lack of clarity about what people might want in terms of their goals of care or disagreements about treatment, these could potentially be triggers for a hospital setting. In any setting, if someone is being considered for transplant, if there are significant levels of distress that are being observed, if patients or families request it, or there are sort of big decisions being made that have long-term implications, like a tracheostomy, dialysis, left ventricular device, being put into a long-term acute care facility, those are also opportunities. And if you're interested in this

particular paper on triggers, this is a very nice paper that came out last year by David Weissman and Diane Meier, thinking about sort of what might be useful triggers for palliative care involvement.

2.2

Care transitions. As we already discussed, they happen in a lot of different settings. They happen with differences in goals. We know care transitions are a high risk event. There is a reason that Medicare is thinking about doing bundled payments because, essentially, we see a lot of problems occurring during care transitions that seem to be -- or a lot of problems with rehospitalizations that seem to be a breakdown in care transitions, and for that reason, it's a great place to actually think about bolstering the transition experience with support.

This was an interesting study actually done in the Netherlands where they looked at (indiscernible - recording interference) who had died in the previous six months, and these are all the different care transitions that these people in the last three months of their lives experienced. And there is no reason for you to see what's actually -- there is no reason to see all the little pieces, but just you can see that people went from home to nursing home to the community health center to the hospital. They're just bouncing all over the place, suggesting, again, that, especially as we get close to the end of our lives, these care transitions become very

important for very close coordination.

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This is a study that just came out in Health Affairs last month that looked at emergency room visits for people who died in the previous — in the last six months of their — I mean, emergency room visits that occurred in the last six months of somebody's life. And in this study, which is from the Health and Retirement Study, actually 10% visited the emergency room on the last day of their lives, 51% had visited within the 30 days before death, and 75% within the three months prior to death. People who came from an African-American or Latino ethnicity were more likely to be receiving emergency room care in the last month of life, people who had severe pain, people who were not in hospice, who had functional dependence and lower levels of cognitive impairment.

Likewise, when you look at other risk factors for care transitions, multi-morbidity, lack of awareness by the general practitioner about where the patient wants to die, again, the goals of care clarification issue, people who were younger than 85 who had an infection or who, again, didn't have palliative-centered goals are more likely to bounce around in the last days of their lives.

How can we improve care transitions? Communication, communication. How do we do that? That's a real -- that's something I hope we can discuss as a group because communication is difficult. Certainly, technology can

help us. My understanding is that there are 55 different EMR systems in use in the state of Alaska. Generally, those EMR systems don't necessarily talk to each other. So an opportunity is to figure out how to improve those communications, despite, you know, the technology not necessarily completely aligning with your needs.

2.2

Treatment preferences and treatment plans. I understand that, in the state of Alaska, there is a program called MOSP, which stands for, I guess, Medical Orders for Scope of Practice — is that right — which is related to POLST and MOLST. The idea, again, is to try to make sure that people have expressed wishes about certain levels of treatment, that we are actually honoring them. This is a step in the right direction. It doesn't mean, necessarily, that people's wishes will be honored, but anything that we can do as providers to make sure we're actually listening to and asking people about their wishes in a dynamic way, recognizing that people's decisions and our decisions change all the time, can be, I think, a way of improving quality of care.

Communication with patients. Patients need to know what to expect. We tend not to do a very good job with that. What to do if they have trouble? A lot of emergency room visits really occur because the caregiver got frantic. They panicked. They didn't know what to do. And then who to call.

In terms of self-management support, Eric Coleman has

done a lot of work in this area. It very much relates to palliative care, in my estimation, because most of the red flags that people experience at the end of life are symptom-related. So if we are aggressive about managing symptoms and we empower patients and their loved ones to know what to do, that will optimize their likelihood of getting the care that they want.

2.2

And then again, contingency planning. What if this happens? What if that happens? Actually helping patients and loved ones know what to do if certain things happen.

This is another sort of guide that can be used when you're thinking about triggers and palliative care from the standpoint of transitions, and they vary depending on sort of where someone is in their illness journey.

So for transition one, it's just about illness burden, and you may think that this person actually has, hopefully, many more years to live, but they have really high illness burden and they're struggling. That might be a time to think about integrating some level of palliative care. What if they do have an advanced illness or actually what if they are actually reaching the final days of their life? In all three of those instances, thinking about integration of palliative care at some level, whether it's basic or specialized, may be beneficial.

Now from the standpoint of Information Technology and

Telehealth, when you deal with any state, in particular, that's rural, technology can be both helpful and also frustrating.

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So what's helpful is, if you actually can get broadband access or you have cables laid down so that people can actually get, you know, wireless access, then you can engage in video-conversing. You can do diagnostic workups. You can manage symptoms from afar. I think this is definitely worth considering. It does not help though if there are problems with access to -- if you can't get wireless access or if you don't have access to any kind of communication line, that's a challenge and that's where asynchronous technology can be helpful. From reading what I did about your health care system, there is some asynchronous work that's been going on, using technology to access remote areas in Alaska. this is a great -- there is a lot of work being done with telehealth along these lines and so I would certainly advocate for thinking about creative ways to use technology. And if any of you are interested, this is a particular interest of mine, and I'll be happy to talk more about it later.

So I want to close with a story, and the story is about someone who was older and who had multi-morbidity and complex serious illness, who also happened to be my mother.

My mother was one of these forces of nature. She sort of swept up a room when she came into it and did that, despite

the fact that she lived with a number of very serious illnesses most of her life. Some of them actually related to what might be considered iatrogenic events. When she had a very big operation at Duke in mid-life, she was given large quantities of blood and contracted Hepatitis-C. She developed cirrhosis, and ultimately, she developed liver cancer. She was the kind of person that, as a health care provider, you would wince when you see her come into the room because she had about six medical charts, and she had every medical problem you could imagine.

Nevertheless, she was very clear about her wishes, and she wanted to live as long as she could, as well as she could, but she didn't want to live if she couldn't live well. So she instructed me that this was what she wanted, and she said, you know, when the time comes, I want to get aggressive palliative care, and she knew palliative care probably better than I did.

And so she had her treatments for her liver cancer, and it became clear that they were no longer offering much benefit. I was hoping we could have her actually experience hospice at home. That was my goal, and unfortunately, she developed tension hydrothorax, and for those of you who aren't from a medical background, when you have lots of fluid in your belly from your liver not working, it can actually push up into your lungs and push your lungs over so much that your heart can't function. So this is an emergency, considered a

medical emergency. And so she came into the hospital and got chest tubes in our Palliative Care Unit.

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What was wonderful about that is, because there was a Palliative Care Unit, she was able to get aggressive palliative care that was focused on quality of life. Her children and her 13 grandchildren, which are all these people here, and her dog were all there with her. She held forth with all the nurses and doctors, which was her way, and died peacefully on her birthday and that's what we all would want, isn't it? I mean, I feel really grateful that she received that, and what I really hope that you, as a group, can achieve is that kind of good quality end of life for every single citizen of the state of Alaska, and I really look forward to our discussion. Thank you.

CHAIR HURLBURT: Thank you very much, Dr. Ritchie. We have some time for any discussion with Dr. Ritchie. We have the two Reactor Panels that we'll be having later in the morning, but we have some time for discussion right now, specifically related to some of the thoughts you've shared with us.

COMMISSIONER HARRELL: Well, first of all, thank you, Dr. Ritchie. I appreciate that. I have a question that relates to some editorialization on your parts of opinion and then a compare and contrast.

So we're in an inverted population pyramid. We're

research-constrained. So in terms of trying to develop policy, even though this is clearly a systems issue. It's multi-factorial. There is no silver bullet. Would you, in your opinion, recommend focus on health care assets, so providers -- systems within the health care industry or focus on ancillary practical help, so now whole of government type of help out into the community?

2.2

My thought and concern is -- and this is why I want your opinion -- that, if we try to hit all of it, we'll probably fail. So when you're making policy, you need to start focusing efforts to get the greatest input. So do you focus on the health care industry and system or do you focus on the practical help, which actually involves more of the government, Health and Human Services, private industry, churches and that nature? What would your opinion be on that? And then I have a follow-up that would be shorter.

DR. RITCHIE: So let me make sure I understand what I think you're asking, which is we have constrained resources, so we have to sort of make decisions about where to use those resources, and in terms of practical help, can you -- that's the part I'd like a little bit more clarity on.

COMMISSIONER HARRELL: So in formulating policy, we can devote money and manpower towards changing our health delivery system, speaking specifically now of health care providers, of doctors, nurses, technicians, health aides, things of that

nature, or we can focus on the community and the practical help that you mentioned, which is, in good measure, outside of the health care system. If you had to choose, where would you focus as opposed to trying to do it all?

2.2

DR. RITCHIE: I don't think you're going to like my answer and that is that I think you have to do them combined because I only think that the system is likely to improve, actually, if the private sector and the community is more closely connected with the health care system. We have to use all those assets in the community.

Right now, they're so disconnected that we actually aren't benefitting as a health care community from all the assets within our private sector. So there has to be some mechanism -- and this is where I think policy can be helpful -- to support that interaction, a much stronger interaction between sort of the health care system, health care providers, and whatever support mechanisms that are occurring outside of sort of the traditional health care model and that's where that whole communication piece comes in.

The opportunity, I think, is to figure out how to incentivize communication and incentivize very clear hand-offs and role supports and that's something that, historically, we have not done a really good job with, but I do think that we cannot not have that support, and especially as we see the sort of rectangularization, as you mentioned, of our sort of

care support systems, and we have to think very creatively about how to do that efficiently. But if the health care providers actually don't know how to work with that community, then I think we won't see the kind of benefit that we would see if there is actually a closer engagement.

COMMISSIONER HARRELL: And so a followup question is that, you know, my opinion would be high contextual cultures - so the Asian culture in particular, Middle Eastern culture, to some degree -- do a much better job in palliative care than low contextual cultures, like we have in the U.S. So compare and contrast those. Pick the top two things that you think, from your opinion, those high context cultures get at and do that we don't do here in the U.S., knowing that one of them is clearly a communication piece, as you just mentioned.

DR. RITCHIE: Interestingly, historically, Asian cultures have done a very good job because the family unit has been such an important part of care and decision-making in supporting people across their illness continuum.

I've spent a lot of time in Korea and in China, and with the one child policy in China and with a lot of sort of the population changes in Japan and Korea with the low birth rates, actually, it's getting more like, sort of, the United States, unfortunately, in terms of people not having the same kind of infrastructure, sort of natural infrastructure to support people who are really sick.

1	So what we are struggling with, I think, unfortunately,
2	we're now beginning to see in cultures that, historically,
3	have not had to struggle with that. However, I will say that
4	cultures that are more inclined to engage in a communal
5	perspective of care tend to experience their seriously ill
6	tend to experience less isolation and that's going to require
7	a lot of creativity for cultures where that's less of a value.
8	You know, if your value you know, I think about some state
9	mottos, and I'll use Alabama's. Alabama's is, "We dare defend
10	our rights." New Hampshire is, "Live free or die." I mean,
11	if your motto is "I want to be who I am by myself," it does
12	make it harder to think about, you know, how you are going to
13	work within a communal context. And so what that means is we
14	have to figure out really and I think this is where
15	Crowdsourcing and using some information technology can be
16	helpful for us how to use things, like Facebook, other
17	social networks, basically people's own created communities as
18	a way of supporting them in a way that sort of our more
19	traditional communities that we've seen in the past and that
20	have been particularly vibrant in specific cultures, you know,
21	we're not seeing. Other questions? Otherwise, I have
22	questions for you, so yes?

COMMISSIONER MORGAN: Well, this is not necessarily a question, but it's a sort of pet peeve of mine.

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DR. RITCHIE: Oh, good. I love to hear about people's

pet peeves.

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COMMISSIONER MORGAN: And this is purely mine. I'm one of the -- I'm not a physician, but I've worked in health care for 31 years. If you go to your first slide, I had an epiphany two weeks ago when an actuary cornered me at the University of Alaska. And if you -- it's basically the global aging.

DR. RITCHIE: Oh, this one?

COMMISSIONER MORGAN: Yes. And what he pointed out, to me, was that I was using a slide during a talk -- I have a slide very similar, and he pointed out that most of the data includes a lot of non-health related deaths, such as accidents and murders, that, when he, as an actuary, pulled those out and compared life expectancies without the factors that don't relate to health, such as auto accidents, home accidents, murders -- and his example was comparing Canada to us. had nine murders in Canada during the statistical year, and I think one suburb of Chicago had 19, but it's mainly in the younger age brackets. I don't belabor the point, but if you actually look at just health factors and longevity of life, those lines change drastically, and I've made the same error. It just -- I got caught of just accepting the same graphs over and over again. Well, because -- and I've got the book here. I'll show it to you during the break. That, if you actually just take health factors and remove things that have not

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related to health, such as murder, such as accidents -- there are two or three others -- the line shifts drastically.

DR. RITCHIE: Which line? I guess.....

COMMISSIONER MORGAN: Well....

DR. RITCHIE:all this is showing is that we're getting older.

COMMISSIONER MORGAN:but the longevity that you were talking about is that our age and mortality, when you compare to other countries, is not anywhere as bad as we keep saying....

DR. RITCHIE: So you're talking about comparing quality of care?

COMMISSIONER MORGAN: Right.

DR. RITCHIE: But actually, all I'm showing here is that, as a country, fortunately because our birth rates are higher, we are not seeing the same proportion of people getting older, but in terms of our longevity, we're going great in terms of increasing our life expectancy. All this is showing is that, as all these -- this is actually not a good or a bad thing. This is just a third of us are over age 65 by that date, and the only reason we're behind these guys is because we have a higher birth rate. These guys have a lower birth rate, and so as a result, they don't have the younger people coming up through the ranks, but this actually does not speak to quality of care or quality of life. It's just actually providing

1 insights on what proportion of our population will be over the 2 age of 65 by a particular time. Yeah; I'm familiar with what you're talking about. 3 Actually, I didn't show any slides of our quality of care 4 5 compared to other people. I just talked about, basically, 6 where we are longevity-wise. And you know, fortunately for 7 us, we're not dealing with it quite to the same degree that Japan is. You know, they're really struggling with this right 8 9 now. 10 CHAIR HURLBURT: It's the dependency ratio, which is..... 11 DR. RITCHIE: It's a dependency ratio. 12 CHAIR HURLBURT: (indiscernible - simultaneous 13 speaking). If there aren't any other questions, you had some 14 questions -- oh, Keith? 15 COMMISSIONER CAMPBELL: Recognizing that we are a rural 16 state and we've got medical pockets of service around the 17 small communities, how would we use our educational system to 18 spread the gospel of palliative care to these outlying 19 physicians who may not rub elbows with their colleagues very 20 often at all? I wondered how we could use our educational 21 system or distance learning, whatever you want to say, to 2.2 really try to enhance the education of these medical providers 23 at all levels.

DR. RITCHIE: So I think that's a great question, and I'm hoping that the group actually can come up with some ideas

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about that. You know, a question I had was the very same thing, which is, what are the things that work here to encourage providers who are basically doing the best they can throughout the state to feel sort of empowered and activated to have this as part of their armamentarium? Do you have ideas about that? I mean, I would love for the group to think about how to answer that question.

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System has a good distance learning. We have a tech school in our town that has one. We -- our hospital, local hospital has through, I think, the Providence system -- the Hospital Association also has some sort of -- I'm not up-to-speed on that, but I think they also have some distance learning capability. It's a matter of the curriculum, I think, and someone saying that you should really take advantage of these things and somebody standing in front of a podium, like you're doing, and broadcasting this stuff out to the people.

Everybody has got the CME requirements. Maybe that's a way to do this. I don't know, but we need to have a discussion so that we can make a policy recommendation.

COMMISSIONER URATA: Yeah. I think, you know, there is work being done on curriculum at the University of Washington, which is sort of our medical school through the WWAMI program. I think they're talking about having classes on palliative care, but you know, it's a priority thing because, you know,

every hour of class, you know, takes up more time and information, but I think that's a good place to start.

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I think our nursing school here in Anchorage should have that in their curriculum as well, and maybe a PA and stuff like that. Whether or not we should have legislation to require that, you know, I'm kind of sort of against that.

And then I think our medical societies should consider adding that to their annual CME programs, you know, when they have their conventions. And then we do have a loose group of hospices, palliative care programs in the state, but we do not have an association or something of that sort. We're still in the early stages of developing something like that. I've heard some movement of people who would like to get all of palliative care groups together, probably in Anchorage, but we're such a small group, you know, we wouldn't have enough money to do that, unless we met at the local tavern or something like that, but that's something that can do that.

I've taken EPA courses and that's training for physicians to train other physicians. I don't know if Dr. Rust has done that, but I'm pretty rusty on -- I'm not very good at that. Excuse me. Not very good at that, but I think trainers can train other physicians as well. I've given some -- a lecture to our medical staff on that, and one of the programs they have is how to give bad news, but I don't know that that was well-received.

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So I think there are many things that can be done and we could recommend, but you know, we have to sort of get people motivated to go to those programs to learn and then to implement it in their practice.

DR. RITCHIE: What do you think would motivate providers to be interested in this?

COMMISSIONER URATA: Well, I think just having this go around in the newspapers, patients requesting it will be a motivator, but also for young, conscientious doctors, you know, who face dying patients and realizing that they're not capable or they're not doing a very good job with them is a good motivator. I think that was my motivation to sort of look into this. And understanding that we do deal with very difficult cases of patients dying and that there is not much that can be done from a medical point of view, but in fact, there still is a lot that can be done to have what people call a good death. And so you know, hopefully, that will be an important motivator.

I think a big thing is the barrier of some of the Medicare rules for hospice and how to deal with the emotions of "giving up," and I think there are ways to deal with that. You know, it's a matter of the patient implementing selfdetermination of what they want, what their values are, and I think, if you look at it from that point of view and go down that road rather than it's a giving up thing, that helps a

lot.

DR. RITCHIE: There is a phrase that I know Rob probably knows, but it's a common phrase that's used in palliative care, which is, there is always something you can do. There is never a time any health care provider should be forced to say there is nothing more we can do. There is always something more we can do. And that's -- part of that is just having conversations with providers and helping them realize what those resources are that are available to them.

COMMISSIONER STINSON: In two weeks, we have a meeting with ANMC/ANTHC to coordinate telemedicine for tele-pain, and we were going invite palliative care to that. That is a meeting on the ANMC campus in two weeks on September 6th. The University of Washington Telemedicine Team and their Division of Pain Management are coming up, and we have a series of meetings to coordinate all of this, and I think we even have the VA invited for that. We're trying to coordinate that, too. So this is actually a lot further along than what a lot of you may think, and the only reason why I've been doing it is trying to help health care in Alaska. That's it.

DR. RITCHIE: That's very exciting. Very exciting.

CHAIR HURLBURT: Could you just introduce yourself, since (indiscernible - voice lowered) so Dr. Ritchie will know your name and then ask your question? Thank you, Val.

COMMISSIONER DAVIDSON: Sure. My name is (indiscernible

- speaking Native tongue) Valerie Davidson. I work at the Alaska Native Tribal Health Consortium.

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So I guess the question I have is, it sounded like a lot of the issues that -- the challenges arise in transitions, and the other challenge arises in communication. And I think, if you look around the state -- I know in our system about half of our patient encounters occur at the village level through a community health aide or a community health practitioner, average village size about 300 or 350 people. I think, if you look around the state in the urban areas, like Anchorage, Fairbanks, and Juneau, there is palliative care that's It may be limited, but it's available. But I think, as a state, we probably should recognize that there is a lot of pro bono palliative care happening at the community level, and what are we doing, as a state, to make sure that the person who cares for their mother as she is passing or their father or their grandmother who doesn't necessarily want to have to come into Anchorage to pass away in a place where nobody speaks their language, the food is unfamiliar -- how do we make sure that the average person who lives in that environment can have those same options? So how -- I mean, I think, a lot of times, we make things more complicated than they need to be. And so for example, we talk about, well, the University system needs to be involved. That's wonderful, but that is a very expensive system. Doctors need to be involved.

Doctors need to be trained, et cetera. That's wonderful for people who have that option, but for a lot of folks in our state, that isn't necessarily an option and that isn't necessarily the preference. So if the goal is patient-centered care and if the goal is patient self-determination, what are we doing to ensure that that opportunity exists in rural communities?

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DR. RITCHIE: I'm really glad you brought that up.

That's something that the more I've learned about the Alaska health care system the more it seemed like that was incredibly important to think about is, how do we really train the whole spectrum of caregivers and offer that opportunity for caregivers who are really on the front lines? Do you have thoughts about strategies because it seems like that's very important?

COMMISSIONER DAVIDSON: I guess I'm thinking of -- I mean, a program that has been really successful for us is the community health aide program, but beyond just the community health aide program, there is a behavioral health program.

There is a dental health aide program, and there is a need for primary care attendants. So how do we make sure that we can make that transition to another -- to meeting the palliative care needs of a community?

On the one hand, we can do that, perhaps, by additional training, creating a new program, but I guess the other --

until we get there, what are we doing to make sure that the
average citizen knows what can they do because it's happening
right now? Family members are already doing that, and if we
know that that's already happening, what are doing to equip
them to really be good advocates and to get their family
members what they need? And the truth is, I mean if we're
really honest, that's not just happening in rural communities.
That's happening here in Anchorage. And so what are we doing
to educate the public at large about how they can be most
effective, what are the right questions to ask, who do they go
to for help, all of those challenges? And the biggest one is
communication, and ironically, that's the biggest challenge is
how do we communicate to people that, yes, this is important;
yes, you're doing the right thing. How do you do that? And I
don't have that answer.

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DR. RITCHIE: It sounds like you've come up with, at least, two things though. One is, potentially down the road, having particular training programs for community health aides along the lines that have been used for behavioral or mental health community aides, that that could be something in the future, and that the second is some sort of more formal public campaign that activates caregivers to know what options are available to them. Is that what you're....

COMMISSIONER DAVIDSON: I wasn't -- for the second part,

I wasn't necessarily focused on caregivers. I was focused on

family members.

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DR. RITCHIE: Well, when I say caregivers, I mean actually....

COMMISSIONER DAVIDSON: All right. Thanks.

DR. RITCHIE:informal -- let's call them informal caregivers then; yeah.

COMMISSIONER DAVIDSON: Got it. Thanks.

COMMISSIONER HARRELL: So it's interesting these comments dovetail nicely with what the Commission discussed last time in terms of telehealth with behavioral health, and this is an extension of that whole process in terms of how you get this information out into rural Alaska and that's telehealth.

That's access through broadband and other areas.

The interesting thing though about your last comment is that's a cultural, nearly generational change. It's taken 40 years to create a culture that says smoking is not good for you and it's held in some disdain now in the U.S., but that's 40 years to get there. Most of us in the room, particularly the providers, have, you know, ads out of magazines from the '30s and '40s where the doctor recommends, you know, Lucky Strike. It's -- that kind of change is a public service announcement-driven cultural change over many years to help our society move, at least in this arena, to a high contextual society. You're fighting inertia to do that.

CHAIR HURLBURT: I think we're at our break. Do you have

any closing comments? Bob?

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COMMISSIONER URATA: Yeah. Just one comment. You know, I think that palliative care should be a skill that all physicians and all health care providers have, and to communicate palliative care -- or the communication skills that are needed for palliative care should go across the continuum of health care providers, and from there, it can spread into the community. I don't want to -- you know, we're so good at providing silos, and I don't think we should have a silo of palliative care specialists, although we sort of have that now, but really, even surgeons should be able to communicate some sort of basic palliative care issues because they deal with pain all the time. In fact, they cause pain by their treatments, to simplify it. So all of it, all health care providers should have the basic skills for communication and the thought process for palliative care.

DR. RITCHIE: Couldn't agree with you more.

CHAIR HURLBURT: Thank you very much again. We'll have two Reactor Panels. Particularly the next one, we're going to be very tight on time, but we have a wealth of folks who have experience, interest, commitment, passion here in our state in these two panels. And then we'll have time for discussion among the Commission members at the end of the day and again tomorrow morning, to give us ample time to reflect on this.

So we'll take a break now, and I'll find out from Bob what he

1	meant by "even surgeons."
2	9:46
3	(Off record)
4	(On record)
5	9:59
6	COMMISSIONER ERICKSON: We're going to go ahead and get
7	started, if everybody could take their seats, please, and if
8	we could have our six provider panelists come sit up at the
9	end of the table, I'd appreciate it. Thank you.
10	(Pause)
11	CHAIR HURLBURT: So if the other panel members could
12	follow Sue Hecks so Sue is going the right way. Yes.
13	Yeah.
14	(Pause)
15	CHAIR HURLBURT: Our first panel, the Reactor Panel, will
16	be from the provider perspective. We have an outstanding
17	panel. Again, I very much appreciate everybody being here.
18	Deb will keep track of the time because our time is limited,
19	and she's got some cue cards that she'll flash. You all
20	introduced yourselves briefly with the go-around, but when we
21	get to each one of you, as you begin your presentation, if you
22	could do it.
23	I'll just mention the names and the scope of what we
24	have. Dr. Rust is going to go first and talk about the
25	perspective from palliative care physicians; Donna Stephens

and Pat Dooley for hospice directors; Annie Holt from the hospital administrator perspective, both as the administrator of Regional Hospital and the President of ASHNHA this year; Sue Hecks from the EMS perspective; and Christine DeCourtney from the tribal health perspective. So Dr. Rust, if we could turn it over to you? Again, just very briefly introduce yourself to the group.

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DR. RUST: Yeah. Welcome, everybody. My name is Steve Rust. I work here primarily at Providence, and I work at the Director of Palliative Care in our Palliative Care Fellowship Program here in -- you know, my wife tells me I have a soft voice; speak up. So I went out and got hearing aides, and it hasn't helped a bit. So anyway, thank you.

What impresses me most is the number of people that are here from so many different areas. It's very, very wonderful to see you all here and the Health Care Commission to donate all their time to come and work and try to help us do a better job.

I was asked to kind of reflect on Dr. Ritchie's presentation, which looked like a fellowship in palliative care in about one hour. So if all of you were able to absorb all of the richness of what she presented, then you're a better person than I was, but I took away a few points from what she said. And we're talking about the need for high context care, and what I mean by that is high quality care via

excellent communication, and we have many opportunities to improve our communication.

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Often in palliative care and in medicine, we're asked to prognosticate. Doctor, how long do I have? And we're not very good at communicating that. But from a palliative care perspective, it's not about prognostication about how long am I going to live; it's functional prognostication. What does my life look like in the future, not necessarily just how long it is, but what does it look like as it applies to me, the person, with my family, with my community, with my work? What options are available to me, and how can I best achieve those?

So when you asked the question about length of life, that's not necessarily the most important question. The question is, what does that look like, and how can we do a better job at delivering that?

So as advisors to our -- and part of our legislature, you know, my specifics, if I had to ask for things, would be to help us communicate better with patients, with families, with health care providers, with each other, try to -- some specific things, you know. Let's develop a common standard format for some of the forms and communication tools that we use that can be applied to people throughout the state, so there are not 15 different forms that aren't necessarily supported by legislation nor by regulation. Let's get -- let's see if we can come together to make this easier to

share. Let's try to develop some kind of central registry or repository for this high context information and that doesn't mean -- and I'm not necessarily saying that government needs to do all this. This is something that you can help as people who inform our legislators and the people that represent us. You can inform them to help bring down some of the barriers that stand in the way of not just the government, but of private citizens and members of the community who, as you can see, want to make a difference and want to help improve health care.

The other thing I heard is education is a key, and everyone knows education is important, but education for families, for patients, for providers, and try to help take down some of the barriers. Dr. Ritchie talked about hospice versus palliative care, and she and I agree 100% that hospice is very, very artificially defined by the Medicare hospice benefit, and the people with Aetna and Medicaid with children, that barrier that makes patients and families choose between active treatment of their disease. Whether it be cancer or lots of other things, it makes them choose either I get all this treatment and I get everything that can possibly be done or I choose hospice. That's a cliff for many families, and it's a process that it shouldn't be an either/or. We know that communication is improved by being able to provide hospice services to people concurrently with what we would

consider regular medical care. Why don't we do that? It costs less. It costs less. People get better quick care. They get better quality. So things that you can do are advocate to the state and also to state representatives and senators. Represent also to the federal government to try to remove some of these barriers and maybe be innovative in trying to make something happen here in Alaska to allow this artificial barrier that exists to be removed.

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The other point that I took away was this: we need support, private and public, to improve, you know, video telecommunication initiatives, to leverage the delivery of the care in our communities, not necessarily -- because we're never going to have enough providers. We're never going to have enough trained people, especially in rural Alaska. So how do we leverage so that the community health aides, for example, are supported? And I hope Christine will talk about this a little bit. How can we support those initiatives, public and private, to make these communications happen that let people receive care and spend their end days with their families and in their homes and in their communities rather than coming here to Anchorage and dying in our Intensive Care Unit where they are separated?

So in closing, you know, I believe those of you haven't should probably read Dave Weissman's, his recent little paper. It's about two-and-a-half pages. It's called "Next Gen

Palliative Care." And palliative care was born of hospice, and now we have subspecialty palliative care SWAT teams that go out and try to help problems, and we are woefully inadequate at that task because there is too much to do. What we need to do is be part of a program that helps educate physicians, providers, families to provide that care in those communities, and there may be different levels, just like you see a specialist sometimes when you actually have to, but you know, 95%-99% of the time, a well-trained primary care physician or provider can really do a great job. So give them those tools to do that.

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And in closing, at least from my standpoint, it's really not about rationing care. It's really about listening. It's about providing the very best quality high-context care to the people or to, you know, our families, to our friends, to our neighbors, to our communities, and palliative care is one of the ways that can happen. Thank you.

CHAIR HURLBURT: Thank you. I think Pat Dooley is next. You can go ahead.

MS. DOOLEY: Yes. Can everybody hear me? My name is Pat Dooley, and I'm the Program Director for Providence Hospice, and I'd like to just preface my remarks by saying I am an R.N. I was a Director of Nursing in long-term care. I've managed home-based services, home health care, waiver care, and now I'm doing my passion, which is End-of-Life Care, and I'm also

a passionate administrator. So what I heard was -- the takeaway was that value is equal to quality divided by cost and that is something that -- that's an equation I try to balance everyday. So that's kind of what I'd like to bring to this conversation.

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The Medicare hospice benefit is actually a wonderful benefit, and it does provide a different kind of health care because it is per diem, which means we get a daily rate. provide medication for pain and symptom management. provide durable medical equipment, like oxygen and hospital beds, and we provide a nurse case manager, a social worker, aides that come out to people's homes, volunteers, 24-hour/7 days a week nursing availability, and a physician -- a hospice medical director who is part of our team. It's very teamdriven, and the patient and family are part of the team. one of the first things we ask when we get into a person's home -- and the key here is that we are providing care in the community -- is, what are your goals of care? So we sit down with the family, and we take time and find out what do they want, and usually, it is exactly what Dr. Ritchie said, was that it's being comfortable. It's being able to spend quality time with my family. It's knowing that I'm not being a burden to my family and that my family is going to have support after I die and that's exactly what we are able to provide.

The issue for Alaska, I believe, is that there is -- I

tried to figure this out. I believe there are four Medicare certified hospices in the whole state, and I've been helping the Fairbanks group just with sort of cheering support and practical information as they're building their program. And we have a lot of wonderful volunteer hospices in the community, and Donna Stephens will talk about those a little bit. But we really -- for a state of our size, because we have such a small population, we really don't have a lot of hospice services out there for people, and people don't know much about it. In the Lower 48, there are hospices on every corner pretty much, and they're in competition with each other, and people know about hospice care. That's not really the case up here.

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So I think what I'd like to challenge us to do is to think about how can we support growing new hospices, helping the hospices we have to mature or perhaps expand or morph into something that's more useful to the community, how can we create all those connections between all of the hospitals, all of the nursing homes, the VA, palliative care, all of those places.

One of my ideas would be a grant, a development grant.

There is -- Missoula had a grant about ten years ago where they were able to bring a coalition of all of the people in their community interested in End-of-Life Care and to create a lot of those connections. So I think there are a lot of

models out there we might be able to look at.

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Something that -- my dream would be to create a virtual hospice where it would be -- where any kind of provider could come and get information about pain and symptom management, about community services, you know, sort of a way for people who aren't in Anchorage or maybe don't have a big health care system to support them could figure out how to provide the care in their community, and it could be for providers, and it could be for -- there could be a part of that for the families and the patients so that people do know what to expect, they do know what to do. There could even be somebody that they could call in the middle of the night that could say, you know, let's -- we're going to work on this together; I'm going to help you with this. And sometimes, all people need to know is that they're doing the right thing, and at 3 o'clock in the morning, that can make all the difference between that last trip to the hospital.

Our goal is that that last trip to the hospital doesn't happen, that people die at home, and we've been able -- and pretty much, between 300 and 400 people in Anchorage die on our services every year and get that year of bereavement support after a death. So I'd really like to see us make this a community effort, and you know, let's take what we've got and make it explode. So thank you.

MS. STEPHENS: Hi, I'm Donna Stephens. I'm the Executive

Director of Hospice of Anchorage, and I think I need to do a little introduction.

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Hospice of Anchorage is not a Medicare hospice. We were formulated in the late '70s when people sitting around a table dreaming about how end-of-life could be better; I was not part of that group. I lived in Fairbanks at that time, so I wasn't here in Anchorage. But Hospice was incorporated in 1980, so we've been here 32 years. We believe in hospice in the original intent of it coming to Alaska. We do not charge for services. We're licensed as a volunteer hospice, although we have paid staff. Our nurses, social workers, bereavement specialists, myself, our administrative staff are paid. We're not well paid, but we're paid.

A little bit about me personally. I am a Registered Nurse. I've been passionate about death and dying probably since I was five and experienced my first family death. Cousins died of cancer when I was in nursing school. Kubler-Ross had just been published, and I was very interested in all of that. So I've been professionally involved in death and dying all my life.

As a brand new nurse, someone asked, when we assigned patients for nurses, who would care for the dying patient, and I was the newest nurse on the floor, and no one would say yes. And oh, I will. I never had to volunteer again, and I learned about dying from people teaching me and their families

teaching me what they were going through.

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What I'd like to focus -- oh, I teach at the University I've also taught in the older learning, lifeof Alaska. learning education program that UAA does for older -- well, they do it for anybody, but mostly senior citizens take it. So I have an opportunity, along with my professional work at Hospice, but in my teaching career to know how much people don't know about End-of-Life Care, and I think that's an area that you really could support and look at. We've talked about the education. It's -- we don't want to think about death. People are very afraid of dying or of not dying right, and people don't know what dying right is. About -- I always say, you know, how many hours have our health care practitioners had in delivering babies? All of them, all of us have had obstetrics. How many hours have those same people in death and dying? Very few. Only about 50% of us can have babies; 100% of us die. It just seems totally -- we stick our heads in the sand, and people do not have good information when they're dying or a loved one is dying about how do we make decisions. We don't want people to die. How do we let people go? We don't know how to do it. So when we're in crisis, you know, if we make the wrong decisions, it's final. So we don't make any decisions. We let life -- we prolong dying often because we're not willing to make a decision that this is the time for someone to die.

Hospice has always been -- the goal is not to prolong 1 2 dying nor to hasten death, to find that sweet balance of allowing natural death to occur, but in order to do that, 3 4 people have to understand that it's legal and it's natural for 5 people to die. And that's where I see the biggest challenge 6 is, is actually, how do we, as a community, talk about dying and understand that it's normal and natural? I think we've moved -- death has moved into our hospital system even with 8 9 hospices. Many, many people still die in hospitals, and 10 medical technology has made it so that people can live longer, 11 not necessarily better. 12 So I would really advocate for education and community

So I would really advocate for education and community discussions about end-of-life, so that people have a kernel of knowledge before they're in crisis. You can't think well when you're in crisis.

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Hospice of Anchorage has written a pilot project that we would love to have funded to further that discussion. As you know, Hospice of Anchorage doesn't charge for services. So just being able to do the services we do, I think, is a miracle of the Anchorage community's generosity in contributing and their concern about end-of-life.

So I think with that, I'll pass the microphone, but I'm very interested in talking with any of you more about this topic, and I appreciate Dr. Ritchie's remarks and so much of what she said is the way we see it at the end-of-life. Thank

you.

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CHAIR HURLBURT: Thank you both very much. If we could turn to you?

MS. HOLT: I don't know how many of you like wandering around cemeteries, but it's kind of something I enjoy, especially the old ones, and there are some very interesting ones in Alaska. And one thing that is obvious that years -- bygone years, people died young. There, you know, are graves for infants, graves for children, and graves for actually some amazingly elderly people back at the Turn of the Century and earlier.

So what that brings me around to is that, in this day and age, many people -- most of those people didn't die in a hospital. They died at home. Many people die in a hospital. I have been -- I, too, am a Registered Nurse. I'm in really good company up here. I've been in hospital administration for many, many years and so the blessing of what we can offer in hospital and acute care in this day and age is we save a lot of people, at least, from death at the moment, but truly, we're all going to die. And sometimes we prolong death, and the conversations about death, although uncomfortable, we now have, and you know, there didn't used to be those conversations. People just got sick or they had an accident and passed away. So death for who and why and when has really changed, and it challenges us, both professionally and

personally.

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I'd just like to see a show of hands. How many of us in this room have had this conversation about what you want when the end comes, however that comes, who has had that conversation with their family? Great. I'm really impressed, and it's a good conversation to have. And I think one of the things that we can do as a result of being here today is to encourage people that we know within our families or our circle of friends to have that conversation with people while they're still alive.

I, personally, don't want to be unnecessarily supported if the outcome is questionable or painful, and I think most of us feel that way, but when we see people in the hospital and they have a family member who has unexpectedly ended up in the Intensive Care Unit, it's anguish for them to wonder what their parent wanted or what their family member wanted and that's where the chaplains and physicians, like Dr. Rust, and the nurses who take care of patients -- really, that's where the work is, but we could prevent a lot of that by facilitating that kind of dialogue now, and it starts with all of us, so encouraging that among our friends and colleagues.

I moved here from Utah, and one thing that the state of Utah did is they did standardized forms, Living Wills,
Advanced Directives, and it's all in a nice packet and available from all of the Utah state government offices, and

you can, you know, fill that out and give copies to your family. That was a statewide initiative many years ago, and I don't think it was especially costly. They weren't fancy paperwork, but they did come in a folder. It was easy to access, and again, made it very simple for citizens there to make their wishes known and have it in writing.

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So I think one thing in the hospital that, over the many years, I've seen improve -- years ago, I was an ICU nurse, and we used to just go ask the family in a moment of crisis, do you want them to be a code or a no code? And the look on their face -- most of them didn't understand. You know, it was Greek what we were saying to them because they didn't what a code was, and we put them in a horrible decision to make a decision, and I do see now that physicians and nurses are much better trained to talk about what resuscitation means in terms that people can understand, a tube in your throat, artificial respirations, defibrillation and that sort of thing. know, we didn't did that -- I'm going to tell you how old I am, but you know, I was doing this 34 years ago, and we'd go, do you want a code or no code, and the family would just look at you like, I don't even know what a code is, but I want it. If it's for my loved one, yeah; I want it. So there has been evolution. We're not perfect yet. There are many professionals that are teaching this in our schools and our professionals.

So death is an inevitable part of life, and I think we -also the final thing to think about that -- my reaction, as I
listen to this, is that I've been fortunate to -- I got to be
the CEO of a children's hospital, and I learned more about
death in the children's hospital than I really have in adult
hospitals and that whole process, it doesn't matter what the
age is. It can be whatever age you are. It can be very
elderly. We have babies in the Newborn Intensive Care Unit
that we are now able to save. Sometimes, I'm not sure what we
save them for. We save kids with chronic diseases or serious
medical conditions that will be their entire lives dependent
on a whole cadre of people.

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I, myself, have had insulin-dependent diabetes for about 46 years, and the physicians told my parents and I, when I got it at 13, that I would die before I was 30, and in those days, that, you know, could happen. Boy, I'm happy to say I'm still here, but people, like me, live a long time now, and again, similarly in the children's hospital, I was amazed how many children with, you know, serious conditions live a long, long life, and it is demanding on society and their families. We can save them, but also there were a number of -- many children who died of cancer and that was really a surprise to me. I didn't realize that, but we had a whole room where their family could move in with them and a whole support team for children and their families, and I think that was one of

the most profound realizations, if for that experience that I 1 2 had of a good death, especially for children. So with that, I will turn the mic over to..... 3 4 MS. HECKS: Am I next? 5 CHAIR HURLBURT: Sue is next; yes. Thank you very much. 6 MS. HOLT: Here, Sue. 7 My name is Sue Hecks. I am here to represent MS. HECKS: the pre-hospital realm, and I'm very thankful that you've 8 9 considered pre-hospital in with this discussion. EMS, within 10 the state of Alaska, is within the Department of Public 11 Health, and many times, EMS is a forgotten part of that and 12 left out of many of the discussions and planning and training. 13 So I'm very pleased to be here today because we are a 14 large part of the continuum of care. We're the first line that these patients see, and I've got some notes here, so I'll 15 16 keep referring to them so I don't kind of wander and get off 17 track. 18 I have been in EMS since 1977 and kind of grew up in the 19 Alaska system. I started in the remote rural community of 20 Seldovia and had served as EMS Chief, as a volunteer EMS 21 Chief. I spent ten years as a elected official. And so I've

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statewide.

I work with all the other directors and all the

worked in all realms of this, moved to the highway system,

of the largest EMS region in the state. I work with EMS

moved up through the system, and now am the Executive Director

services as well. So I'm here to represent that voice today.

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One of the takeaways that I got from Dr. Ritchie's presentation was that there is going to be a huge impact on the EMS system in the state as our population ages, and we are facing recruitment and retention issues statewide and nationwide for EMS and fire services.

In Alaska, the EMS system, the majority of the calls come from the larger urban areas and the metropolis of Anchorage, if you will, but the majority of communities and responders are in rural Alaska. So it's very, very challenging to keep your personnel, and frankly, when we talk about this very topic, it's against our grain. In EMS, we are trained to save lives and resuscitate patients. So when it comes to the end-of-life aspects of things, it really goes against our training and our desire to help people. However, it is an integral part of the system.

The Comfort One Program. How many of you are familiar with the Comfort One Program? Good. There are a lot of hands that did go up.

The Comfort One Program in Alaska was established in 1994 in statute, and it was designed -- it was patterned after a program in Montana and designed to allow patients' wishes regarding resuscitation to be honored. It provides a statewide system for identifying patients who have the DNR status, and it is a program that is between the patient and

their physician to determine whether or not they want to be enrolled in that program. It allows statutory authority for prehospital personnel to withhold treatment. It also carries pretty stringent regulatory -- you know, we are -- when EMS responds to a patient, we are statutorily and regulatorily bound to treat that patient. However, if we're responding to a Comfort One patient who is enrolled in the program, we are regulatorily and legally bound not to treat that patient and provide palliative care, and there are some pretty stringent fines, if we don't honor the Comfort One. EMS providers receive training in the program through their EMS classes. So it's a part of every EMS person's training.

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I brought today, to the table, some of the points about the Comfort One program. We see it as a very valuable program in the state of Alaska, but it's not well-known. It's not a program that clinical providers work with on a frequent basis. So they may not be as familiar with the paperwork of the program and how to initiate the program, and the families certainly aren't aware of that program, unless it's brought to their attention by the caregiver, but it allows the patient, and the family, to make some decisions about their end-of-life choices, and it's designed for terminally ill patients. It's not designed for people who -- well, you know, 100% of us do die, but it's not designed for -- because you're aging that you get a Comfort One. It's designed for people with a

diagnosed terminal illness for end-of-life decisions.

And some of the recommendations I wanted to bring to the table for the maintenance and maintaining of the program. I know there was discussion of the POLST and the MOLST today. While there is discussion of that and I understand they're working to resurrect that program and evolve that program some more, it currently it doesn't have statutory -- statute behind it to enable prehospital care providers to withhold resuscitation.

Comfort One is the only program that is in place that enables that, and a couple things to point out are that the regulations for Comfort One -- the statutes have been updated and maintained, but the regulations that go with that do need to be updated. There needs -- it's a program that is kind of an unfunded program, if you will. It lies within the section of emergency programs, managed through the EMS unit within the section of emergency programs in Department of Public Health. That unit has been having some staffing issues, and currently, it doesn't have anyone, really, to oversee the program, except for the EMS Unit Manager. So the EMS regions have been the ones who have to administer the program.

Our region, in particular, is probably the largest user of the Comfort One program. The regional offices provide the forums to the clinical facilities, and we try to provide training and outreach and things, but we, frankly, don't have

the manpower or the funding to be able to do that. So education of physicians, the staff, and the public is a huge need for that program.

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There is a lot of public confusion about Comfort One and Advanced Directives. Many of the prehospital providers will get on scene and somebody will hand them their Advanced Directives and say, well, here, you know; here is their Advanced Directive. Well, that only kicks in when they get to the hospital. That doesn't work in the prehospital realm, so that's an issue.

So outreach and awareness of the program is very important, and whether it moves into the MOLST/POLST program or stays Comfort One, that's a key element that needs to be involved.

And one of the other suggestions was to have a registry where there would be patients enrolled in the programs would have a registry involved, so that dispatch centers could then get into the registry and verify that services are responding to a Comfort One patient so that the regional offices, when people come in to get the bracelets or issue paperwork, et cetera, that there be a place where we could go that we could verify that someone is or is not in the program and would also enable them to rapidly -- if they want to terminate their Comfort One, that that could also, you know, readily go in and be able to make the changes as the changes in their health

care and the decision-making goes.

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Prehospital is not just the ones that pick up the patients, and many of these complex patients, EMS sees frequently because they have multiple trips to the hospital.

In rural Alaska -- and particularly, and I really appreciated a lot of Valerie Davidson's comments to the Commission. In rural Alaska, many times, the prehospital providers are the ones that do the welfare checks. They get called because Uncle Bob fell out of bed, and you know, they need help getting him put back in. Can you come check Aunt Martha because I'm not sure if she needs to go in or not?

There are many challenges as well as getting patients from rural Alaska into a definitive care facility for their needs, too. So there is a whole gambit of things that come with the End-of-Life Care and the prehospital realm.

I really appreciate being able to be here today, and if you have any questions, please don't hesitate to ask.

CHAIR HURLBURT: Thank you, Sue. I think we probably will have some time at the end for questions from the group or discussion. We have one more. Christine, if you could go ahead, please?

MS. DECOURTNEY: Yes. I'm Christine DeCourtney, and right now, I am with the Alaska Native Tribal Consortium, where I develop programs in cancer, everything from prevention through the end-of-life.

Does anybody remember the story when you were a kid that there was some guy that wore tons of hats and there was a monkey involved? You remember that book? That's what I'm feeling right now, as I hear Dr. Ritchie speak and everyone else.

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So the first hat I wear is as a daughter, where my mother, in Michigan, broke all hospice records by being in hospice for three years for a cardiac condition. The thing that wasn't mentioned is that you can recertify every six months, and for people that just think six months is it, I say, listen, my mother was there, breaking all the records.

Number two, I'm not a nurse, but my sister was a nurse, and I'll just -- a couple things because she is a retired nurse from a long time ago, and one of her duties as a nurse on the floor was to give her patients a massage every night, and they did that so they could really understand how the patient was doing by hands on, by talking to the patient, and seeing. And as she also said, when she checked vitals, she wasn't just checking vitals. She was checking skin. She was doing everything. We have moved so far away from that model of comfort and care that we must remember that that was, I think, way ahead of a lot of what we're doing now.

The next one is as a widow whose husband died less than 11 months ago, with palliative care and hospice support, the worst possible death ever. And being involved in palliative

care for all this time, I couldn't stop it and that must never ever happen to anybody again.

The first part of that though was, just out of
University, I was working on EMS system development across the
country. I was in Michigan, and in part, was the 911 system
that -- older people may remember that many people fought 911.
It was taking away rights. It was taking away everything.
The only part that worked well with my husband was that I
called 911. They asked if I had a Comfort One. He had a
Comfort One on file. I said yes. They called the fire
department/paramedic system. They arrived quickly, took
fantastic compassionate care for him, and took him to the
hospital. That worked beautifully, and I feel proud to have
been a part of that many, many years ago.

The next one -- and again, this is from the comments -- is as the Coordinator of the International Telehealth

Palliative Care Symposium that was based in Anchorage at

ANTHC. It came out as -- we had a -- ANTHC had a big

palliative care grant that I administered for education, and

with all the providers in town, we would put on palliative

care education symposiums, bringing people in from the Bush,

plus the best speaker. And as the grant ran out, we tried to

figure out how we were going to continue it and came up with

the telehealth because ANTHC is a worldwide leader in

telehealth and telemedicine, which sometimes people forget.

With the help of Dr. Rust and some others, we offered the best in telehealth -- through telehealth, palliative care education worldwide, free CMEs, free registration, and speakers from Spain to New Zealand, throughout the U.S., Canada, everywhere donated their time.

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The first year, we had ten countries participate, 300 registrants. The second year, we had 600 registrants with 20 countries. The only problem was we could not get Anchorage physicians to be part of it. We made it as easy as we could the second year. They could join even for an hour on a topic. We added something which we call JITT, which is Just In Time Training, which meant all the speakers' videos and everything were kept. For instance, if you had to a family meeting, which many doctors don't do, they could go back onto the site and refresh themselves from that training. But I want to repeat: almost no private doctors in Alaska were willing to even do that.

The next one was I was in Bristol Bay for ten years after Dr. Hurlburt was there and developed the Helping Hands program under Dr. Ira Byock with the Excellence and End-of-Life Care program. Our belief was that we could help elders and other people die at home with support. At that time, if an elder left the village, it was a terrible goodbye and that was the end. The elder would die very quickly in Anchorage because of the food. It was too expensive for anybody to visit. The

worst part of it was that the village and the people were denied completing the circle of life, in helping the people who cared for them die. And so we were successful, and as a monetary thing, which is very important, we proved we could save two Medivacs per patient. That's a lot of money in Alaska.

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So after that, I went to the SeaLife Center for three years, where I did the same thing for animals, and I like them better. They didn't talk back. But now I'm with ANTHC, and one of the other things I'm doing now is developing the palliative care program for the Alaska Native tribal health system.

But one (indiscernible - voice lowered) I'm going to have to do is tell you about a death, one of the best deaths I've ever heard, and it was my cousin's husband. And Wayne was a very retired, respected educator. He was 71. Four years ago, he had had a cardiac arrest on kind of a remote golf course, and through EMS and then to the primary care hospital and then to the major city one, he made it, was in the hospital a long time, but came out in excellent condition. However, about three months ago, he had some stomach issues and went to his G.P., and they tried a number of things and then they ordered some blood work and an ultrasound and then a CT, and he was diagnosed with pancreatic cancer, which had spread to several organs.

For those that don't know, pancreatic cancer is very, very difficult to diagnose. It does not have a long life.

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This was still handled by his G.P., but an appointment was set with an oncologist. They made a decision not to do a biopsy because it was painful. They knew what to do. Wayne's cardiac condition stopped the idea of giving some very, very aggressive medication, chemotherapy, which would probably lengthen his life just a bit. Palliative care was involved immediately. His cardiologist called to discuss which meds he longer needed. He didn't need Lipitor for cholesterol anymore.

A nurse and doctor came to visit and explained what was going on. The second day, an occupational therapist came to teach and try to look at his situation from bed to bathroom to whatever, to help measure steps, to show him how to do what needed to be done. Also immediately, for two hours a day, a respite worker came in, and he helped bathe Wayne and everything else, so Wayne's wife could leave.

A condition, which is called ascites, is very often experienced by cancer patients, which is a huge build up of fluid in the abdomen, very, very painful, and paracentesis is what removes it. Wayne had it done twice at the hospital, but grew weaker.

By the way, paracentesis is denied patients under palliative care in hospice in this country.

A doctor say he would come to the home and do it, if needed. As Wayne -- Wayne was an ex-priest and so his mass and his gospel and everything was very important to him, and he was still able to arrange this.

They thought that maybe, you know, he was dehydrated and so somebody came in and gave him four hours of hydration therapy, which helped for a little bit. Doctors and nurses were available 24 hours a day.

One doctor came in and had a discussion with him about asking him if he was afraid to die, and Wayne said, no; I'm not afraid die, but I'm afraid of pain. And the doctor said to him very clearly, this is why I am here. I am here to make sure that you are not in pain and are comfortable and as conscious as much as possible.

So they wanted Wayne to move from the bedroom to the living room with gardens, so he could see the gardens. So they called EMS, who promptly came and carried Wayne down on the hospital bed in the living room where he died, surrounded by his family. No one asked about money. Nobody asked about cost. They never bothered my cousin. This was in Toronto, Ontario, Canada. Enough said.

The ANTHC system will have four components. This has been approved. The first one is that there is going to be developing and implementing an in-hospital palliative care consultation program, but as opposed to just seeing in-

patients, this program is going to identify patients in the clinics early. Palliative care begins at diagnosis.

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You have, I think, a book in your packet that I had written. We believe that palliative care begins at diagnosis. Everyone is part of the palliative care team in the health care system, from the housekeeper that comes in to see the patient and who might talk to them to the maintenance worker that comes and changes a light bulb. Palliative care is everybody's business, not just the medical team.

The second phase -- and remember, the Alaska Native tribal system, one, is a public health system, is birth to death. It has a limited amount of money. It is also the only system of care for everyone that lives in those remote communities, and they are not just Alaska Native that live there, too.

So therefore, by providing palliative care early, we hope to reduce ER visits, Medivacs, hospital admissions, and ICU admissions. And again, remember that everyone is involved.

And it is really providing some of that old-fashioned comfort and care that my sister had to do as a nurse.

The second phase is we're going to, in the urban area in Anchorage, evaluate the impact of either the availability or the lack of home support services on patient well-being and cost in benefit and ER and ICU and in-patient admissions.

The third part is that we're going to develop the remote

palliative care component, which is working with the physicians in the regional area and the community-based workers. A huge amount of that is going to be through telehealth. We use telehealth for family visits. A cart is wheeled up to a patient that is dying near the end of life, and the village wants to say goodbye. We use it for communication between doctors and the health aides. We use it for education.

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The people in the communities are very, very well-versed in telehealth. They'll all crowd into the clinic and have a joyous time. We had a 20-year old that was dying of advanced breast cancer, and it had spread to her brain. And so just before she went into surgery, it was set up so that two villages were on the screen, her paternal village and her matriarchal village. Babies, elders, you name it were there with the grandparents in the middle. This family that was there who was very stoic -- they were Yupik -- I've never seen them so animated, laughing in Yupik, showing the new babies on the screen and then they all said a prayer in Yupik -- or they sang a song in Yupik, a prayer. This is palliative care. You know, it's not just the medicine.

And the last one that is most difficult is we're going to look at the feasibility of establishing a statewide hospice program with potentially the billing and so forth, if Medicare doesn't change, based at ANTHC to help the regions.

So those are the four phases that we want to do. So the specific things I noticed were that there is no hospice house in Anchorage -- or in Alaska. That is shameful. That is shameful with the amount of disease, the aging of the population in Alaska. The Hospice of Anchorage had done a study a few years ago, but then politics intervened and nothing happened about it. That needs to be supported by this group and the State.

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Especially in the rural communities of which there is a lot and the geographic problems -- oh, good; I've got three more minutes. That's a positive way of looking at it. You know, the PCA program, the Personal Care Attendant program is important.

As we talked about, things have changed. We have difficulty getting elders to accept this. Elders were proud when their granddaughters took care of them. They were ashamed when they were paid to take care of them. And so one of the books that we developed, a booklet and a story, was saying that things have changed in the villages. Many years ago, elders did all the schooling. Many years ago, you just ate at everybody's houses and now there are restaurants. And now everything, you know, is a cash economy. To stay in that village, you need money, and for a granddaughter to be paid to take care of somebody is not shameful. You know, it is saying they want to be with you and they want to say there with you.

So I think, you know, as a whole -- and again, it's not 1 2 just Alaska Natives up there; there are a lot of other people -- supporting programs that save dollars -- and those are 3 4 Medivacs, and we can easily prove how those are saved. When a 5 doctor, a nurse, or someone can talk a family down or a health 6 aide -- one of the things we want to do and is not funded, but I believe in strongly, is sending a nurse home with a patient to look at the environment, get the patient settled, and help the health aide. You know, they're going to call anyway. And 9 10 so if you know what it looks like in that village -- there is 11 a universal rule for hospice or palliative care. I don't care 12 if it's the biggest city or the smallest one. You have to be 13 in a safe environment, and you have to have a primary 14 caregiver. Those rules are a must.

And so you know, the idea of sending a nurse home for one visit is going to be a big cost saving, if we can fund it, a statewide palliative care formulary, so that everyone can access the same state-of-the-art drugs and are not different - different parts of the state. That can cause real problems when trying to get medications to the remote areas.

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Those are kind of the main things that I wanted to bring up, but I do want to emphasize at the end that, in many ways, the tribal health system, because of necessity, has managed to be innovative, creative, and figure out how to do things, and telehealth is the other leader. Providers and patients are

very comfortable using that system, and I think we can help the State, as a whole, do that. Thank you.

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CHAIR HURLBURT: I'd like to thank all the members of the Reactor Panel. We have about four minutes, and we are going to need to stay on time because we have another panel, but I wonder, Dr. Ritchie, if you have any observations, comments, or questions for any of the members of the panel, based on your experience and what you've heard here about what's going on here in Alaska?

DR. RITCHIE: Well, I mean, my primary observation is that there is room for lots of optimism. There are so many dedicated, passionate people who are doing very good work and who have creative thoughts and creative ideas. I love hearing about what's going on with telehealth, with the creativity that's being used in the EMS system, the idea of a registry that allows for quick, you know, checking seems like a really great idea, really thinking about how to support hospice development across the community in creative ways, potentially using telehealth. Those all seem like very practical approaches to actually increasing access for palliative care, and there are a lot of pieces of the puzzle that are already in place.

CHAIR HURLBURT: Yes?

MS. HOLT: May I just add one thing from the hospital standpoint? You mentioned that -- and this is true -- for

Medicare patients who are readmitted for the same condition, hospitals are penalized for that, and it's a curious thing because of all of the data that you've shown for chronic diseases. Often times, there is no -- they need to be in the hospital. So I think that's something that our government, and as a society, we have to look at because chronic disease sometimes exacerbates, and I thought your graphs were very helpful in showing that, and they need to readmitted. It wasn't because there was some deficiency in either their outpatient or inpatient care. And also hospitals do have many bioethics consults and resources that we bring to bear for those patients as well, at the time that they are in. Would you want to comment a little more on that?

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DR. RITCHIE: The whole issue of bundled payments in management of rehospitalizations is an intriguing phenomenon that's going in our country, and certainly, there are probably stories that each of could tell of people who have been discharged prematurely or who haven't had the tools that they needed to be effective outside of the hospital, but there are many instances when people — that's the exact right place for them to be, is in the hospital, and especially with things like heart failure. There may be some fine—tuning that may be difficult to accomplish in a different kind of setting.

So I think it's going to take a lot of creativity for us who are in health care systems to figure out how to address

bundled payments. And the only thing that may be good about bundled payments is that it may facilitate increased communication inside and outside of the hospital, and if it can facilitate communication, since that's one of our big challenges, then that may be one of the positive elements, but it certainly is going to be a challenge, I think, for hospitals across the country.

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CHAIR HURLBURT: Thank you all very much again. We very much appreciate your being here. I think we'll move on to our next panel, and this will be Community Perspectives. members of the next panel -- again, I'll ask you to introduce yourselves. You did introduce yourself briefly earlier, but it will be the Patient/Family perspective. Virginia Palmer, who is President of the Foundation for End-of-Life Care in Juneau, as she mentioned earlier, she'll be bringing that perspective. Senator Fred Dyson, who is has had a real concern and interest in this area, will be speaking from his perspective. Ann Marie Natali, who is a Medical Ethicist here at Providence -- and I know that position was vacant for some time, and they were just so delighted to get you here, and we hear good things about you being here. And then Rick Benjamin, who is the Director of Spiritual Wellness for Hope Community Resources, to bring the Faith Community perspective to us here. So Virginia, I think you are first on the list. If you could just introduce yourself and go ahead?

MS. PALMER: Hi, I'm Virginia Palmer, better known as Ginnie to all my friends. I think I've been Ginnie forever. My mother was the one that used to call me Virginia, but you've got to do what you've got to do.

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I'm thrilled to be here today. I am so impressed with this group and what you're trying to do. It's really needed, and I'm excited about it.

Being a person who dealt with my husband, who had rheumatoid arthritis from the time he was 26, but continued on being a commercial fisherman, a farmer, and also a senator in the state of Alaska, it was -- he was a very active person. Then he developed congestive heart failure. Then he had a defibrillator put in. And then he got Alzheimer's. So we kind of went down. We did pretty good until we got the Alzheimer's. Then we recognized, well, that wasn't going to -- we weren't going to beat this. And we were very fortunate because we were Tier I. If anyone is in the State office, they know what Tier I means. Your health care is well paid for.

So we had lots of opportunities, and one of the things I learned in that was that people are afraid. The biggest thing you have to deal with as doctors is fear because they're being faced with limitations in their body, limitations in their mind, and all of a sudden, there are -- they come to a doctor, and the doctor needs to be able to look at them and treat them

like a person and not like a battlefield. They need to be able to say, hi, how are you? With our doctor, he would come in, and the first five minutes would be talking about the political scene in Alaska, all the way up until the end. And of course, Bob's political scene, as he developed Alzheimer's, changed because, pretty soon, Governor Hickel was back in power and Governor Egan was there also. So -- but that introduction for Bob was wonderful because he was a person.

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I was in the room all the time, but the doctor always talked to Bob. He looked at Bob's eyes and talked to Bob. He knew I was going to be able to hear, but that's really critical that you treat your people like people. And one of the big things -- we were in hospice, and I feel one of the things that needs to be done with hospice is doctors and people have to put the hope back in. Hospice is hope for people because it means that all of their fears will be handled toward the end of life. This is really important. It's hope. That's what hospice is about and that's the way we should address it. And when you talk to people about hospice, you should address it in that way. It's really, really important to have them do that.

Bob was also on Comfort One, so Bob died at home, and he was with me. I had the cell phone of the doctor, and when I recognized that something was happening, I called the doctor at home on the cell phone. Now I don't think a lot of doctors

give out their cell phones, but it's really critical. You know, it gives, really, comfort to the patient to know that they have that opportunity, and in fact, if a doctor had two cell phones -- I mean, the hospital could provide him with one cell phone, so that could be kind of his patient phone, but be able to call him and say, I don't know what's happening, and I was asked, well, was Bob eating, and I said no. He hadn't been eating for four days. And then he said, it's going to be soon. And so -- and it was. It was that night. I was watching the Antiques Roadshow after I had taken Bob to the bathroom, and Bob died. And so the -- and it was wonderful to be able to have that opportunity to be with Bob when he died, and Comfort One was wonderful. We had people -- actually, we called the hospice nurse, and she came, and the mortician came, and we were all taken care of.

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I think it's also critical to understand about how fragmented for the patient our care system has become because we have specialists. I mean, Bob had a rheumatologist, and he had a cardiologist, and he had a family practitioner, and all of these different people. Well, every time you went to one, they would give you medicines, but the medicines were all from different people. And so when you were asked to come into the doctor's office, we always had this battle, especially towards the end of Bob's life, should we bring all the medicines that he was on, which is very true because he was on a lot of

1	medicines, or just the ones that related to that doctor? And
2	what about all the supplements that he's on as well? I mean,
3	it was a huge thing.
4	So I recently talked to a retired doctor from Chicago.
5	Do we have to leave? I set it off.
6	CHAIR HURLBURT: I guess we better be good. Sorry.
7	Thank you.
8	11:05
9	(Off record)
10	(Fire alarm)
11	(On record)
12	11:10
13	CHAIR HURLBURT: I think we can go ahead and get started.
14	We've probably lost five minutes or so there, so it wasn't too
15	bad and that was our healthy stretch break. It wasn't planned
16	there, but sorry for the interruption. Ginnie, if you could
17	go ahead and pick up from there? And we'll plan to run about
18	five minutes late there, but we will need to try to end about
19	five after 12 because our time for lunch break is limited.
20	COMMISSIONER ERICKSON: Yeah. And one of the things I
21	just asked Ginnie to do, if she wouldn't mind taking a couple
22	minutes to introduce her husband because I had a couple people
23	come up on the fire drill break and go, is that the Bob
24	Palmer, so I said, yes; it was.

MS. PALMER: Yes. It is. Well, I called him the Bob

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Palmer. It was W.I. Bob. Walter I. was his real name. He worked -- he lived -- homesteaded in Ninilchik, Palmer. Alaska in 1948, raised seven children, one of which is here. My stepson, Jim, is here. I'm Bob's second wife. He was a senator here at the state of Alaska and worked with Jay Hammond. In fact, he had great stories of, when Jay first became governor, he and Jay living in the mansion all by themselves before Bella came down and before they had any staff. And so it was amazing time, and he really contributed, and he certainly contributed to my life, and he lived life fully, all the way up until the end. I mean, it was amazing that he carried all of the different elements of a disease, but we were really fortunate because we were really talked to people and talked to doctors.

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When you talk about palliative care, for example, when I was in Arkansas and Bob started having a lot of rheumatoid problems, they introduced me to a pain doctor, and his name was Dr. Money. Now, isn't that a great name for a doctor?

But he was a very good pain doctor and so he gave me about an hour/hour-and-a-half quick lesson on how to manage pain. And so I became in charge of Bob's pain pills and managed pain.

And you know, people are amazing. I mean, when you talk about palliative care -- now I may be very naive in this, so you have to remember that, but that families can, a lot of times, step up, and they can really take that place in a patient's

life. It doesn't have to be a doctor or a nurse, if they could be told how to do this.

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When Bob developed staph in one of his elbows -- I used to call him Bionic Bob because he had replaced -- so many different joints had been replaced, and he developed staph in his elbow, and he had to have Vancomycin with an IV drip, and there were three little tails coming out of -- underneath his clavicle, but we made it. I mean, they showed me how to do it. Of course, I nearly fainted when they pulled it out and I realized it went into his heart. That was a little scary, but it was after-the-fact and so we got through that.

But you know, I really feel strongly that you guys are on the right track here, that, when I -- I started to tell you I talked to this doctor in Chicago, and he's retired, and they have a new program in Chicago where the retired doctors are taking over patients in their homes, and he has a little block -- well, several blocks in one area of Chicago that he visits these patients about once a month or more often, as needed, and he actually goes to their home. And he's the one that said -- it's really interesting when he says, well, show me all your drugs, and they come out with this huge thing of drugs and supplements and everything that they never bring to the doctor's office when the people who are working in an office ask them to bring it. And he said it's very effective because people want to be home and they want to be in their

own surroundings, and when he is there, if he sees something that needs addressing, then it should be addressed, but doctors don't do that nowadays.

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You know, when I was growing up, we had a family doctor that always came to our house, but that just isn't done. I realize probably population and expense and everything, but that type of thing -- if a program, like that, could be put into effect, it would really be wonderful. And in fact, I'm really complimentary to our medical profession here because I've seen things change over time.

Now I'm 71 now. So when I grew up, my mom had my brother. She was in the hospital for a week after. Now they don't do that. They kick you out the next day or sometimes the same day, but that's very positive for the family overall and for the person when they have a regular birth, you know. And when you look at short stay surgery, I mean, they didn't have short stay surgery and that's a wonderful thing because families go in. They can have these medical procedures in a safe environment and be able to come home. And so all of these things you've been stepping toward where we are right now. So change is a real opportunity.

A hospice house would be fabulous. It would be fabulous to have a hospice house. In many areas of the country, we have people who are living under bridges that are homeless, and when they develop cancer or anything else, they have

nowhere to go to die. And so a hospice house would really be wonderful and really wouldn't be that difficult to put together, if we can set in the guidelines, and I think that you all have that capability of doing that.

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We are -- as the person who is the head of the Foundation of End-of-Life Care in Juneau, one of the things we do is we believe in education. So where you guys are talking about educating doctors and nurses, I'm talking about educating people. And so we bring in a speaker every-other-year. We would do it more often, if we could, but right now, it's every-other-year.

On September 21st, we are bringing Dr. Lenny Leary from Hawaii. We are getting, what, CPUs -- or what is it?

COMMISSIONER URATA: CPU; yes.

MS. PALMER: CMUs? Anyway, we're getting that for nurses and for social workers, and they're getting them for the doctors, too, which is wonderful. And what she's going to be talking about is helping to die and how do you tell a person how to die. It's going to be televised. It will be on 360 North, so it will be shown up here in Anchorage as well. DVDs will be available. And prior to her talk -- I don't know if you all have seen this, but there is a videotape out where they interview people who are dying and how they feel about that and that will be also on that -- also just prior to her talking.

So we're trying to educate people from the -- we're trying to educate people that dying -- sure; you're afraid to die because it's like you're watching a really good movie and you have to leave early. And so it's really important to be able to look at your life and say, yes, I've had a great life. I've loved every second of it, and I'm -- you're always a little afraid of death, so I can't say I'm not afraid, but I think that's the big thing and that's what doctors need to be able to do. They need to be able to reach out, look the guy n the eye.

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When Bob found out he had Alzheimer's, a nurse told him over the phone, and he was shocked, but it helped us, really helped us that she was so blunt. She didn't realize she was being so blunt, but she was so blunt -- because we could get our affairs in order and that's what -- I know that -- I see my book out there, or the book that my foundation put together. Thank you. And in that book, that's what brought that book about is because I discovered that people didn't know about all these things.

For example, Bob always changed the oil in the car, and I did the laundry. Now when Bob died, the car suffered because I didn't know how to change the oil. And one thing about it is I knew Bob's Social Security number because I always filled out the health care things, but if I had died, Bob didn't know my Social Security number. So you all may feel that you are

ready to move forward, but do you know your partner's Social Security number? Because in order to file your death certificate, that's something you have to have. That's as good as I've got for you.

CHAIR HURLBURT: Thank you very much. I liked the part about the movie. Senator Dyson has had an interesting concern, both as a leader in our community and in the legislature and related to friends to talked with him.

SENATOR DYSON: Impressed to be here amongst you all. I don't think any of you have treated me. I hope you know that Representative Keller has been a chair of the House Health and Services. I have been on both the House and Senate side for many years, and Senator Bettye Davis is here, was the past Chair of the Senate Health Committee. And all of us are facing involuntary retirement here in November, but I suspect that, at least, some of us will be around.

I'm both a consumer of health services -- this hospital,

I carried my oldest daughter in here with both Hepatitis C and
mono. She was a classmate of Ann Marie's and so on, and it
there was potential she wouldn't make it, and she walked out
of here, and we were delighted.

During the time I was Chair of the Health Committee, we went through the bill on end-of-life decisions, and I think Senator McGuire was responsible for that. I thought, at the time, we did a good job, and you all can tell us things that

need to be changed.

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I've gotten very involved here the last year-and-a-half over the whole issues with end-of-life things and the issuance of DNRs, Do Not Resuscitate, and the two or three variances of that, and we've had some extensive, and sometimes pointed, discussions with leadership here at Providence, and I think we are coming to a very mutually agreeable conclusion on that.

And Dr. Rust here can clarify or contradict anything I say, if I don't get it accurate. But the existing law on this -- and it's Title VIII -- was assembled piecemeal, and in my view, it's illogically stated there and it's not organized as well as it should, and that opinion was also stated by Duke Law Review folks.

But as we've worked together here with the folks here at Providence, we've come to the following things I think we agree on, that the issuance of a DNR should never be a surprise to the patient. There ought to be extensive discussions ahead of time and come to agreement, if at all possible, and lots of lead in discussion on it, and the patient should understand, if a DNR has been issued, that doesn't preclude both the palliative care that you've been talking about, but also doesn't preclude appropriate response if there is a sudden and unexpected condition that comes up. You know, a guy is being operated on for a broken leg, even though he's got terminal leukemia, and on the operating table,

he goes into an arrest. So I think we're in agreement on that, but the patient often doesn't understand what the DNR says and jumps to the conclusion, if they have an unexpected problem, nothing is going to happen, and I think we're in agreement that folks ought to understand that sudden and unexpected conditions will be treated.

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If a patient disagrees -- and when I say a patient, I mean a competent patient or their surrogate who has authority -- doesn't want the DNR in place and there is a disagreement with the care provider, there ought to be an appeal process of some sort, come to the ethicist or whatever, or if there is still not reconciliation on it, they ought to be able to transfer to another facility that would agree. And it's my view that, during that interim, hours or days before the transfer happens, that the patients wishes should be in place. I think we may disagree on that, but that's -- I think we're close on that one.

The thing I sense that we may not have concurrence on yet is, can a doctor issue a DNR without the competent patient's agreement? And I have several good friends in this community who are in doctors, and they have told me they've gone along with the patient's wishes, but they were wrong, and the family was literally authorizing the torture and discomfort, you know, and the doctors involved had some real reservations. I think that -- and this is a decision for you all in the

practice -- the DNR order, if it's on a piece of paper posted on the footer or above the head of the person, should say that it doesn't preclude treatment for sudden and unexpected things. That would be a lot of comfort to the patients that I've talked to.

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Also if a patient shows up and the facility or doctor doesn't know that a DNR has been issued, they should treat the patient for however they present themselves and that you, as a medical professional or a facility, ought to be able to ignore the DNR if you, in your medical judgment, feel it's inappropriate. And a doctor friend of mine, a friend of 40 years, was very upset with one of the facilities in this town because a patient of his showed up, and nobody called him, and he had been treating the patient for an underlying terminal condition for several years. DNR was issued, and the patient And my doctor friend, who was the treating physician for the quy, was quite upset that he was not included in the loop. Now I don't think that's a policy. I think that was, hopefully, a one-off situation, but it certainly needs to be -- make sure that, if the records are available of who is the treating physician, they are in the loop on those decisions.

And then another issue that came up was, how far in advance should a DNR be issued for a first person that's terminal? And I understand that I don't get all the accurate information, and people that talk to me sometimes have a spin

1	on what they're telling me. I know that never happens to any
2	of you, but it does to me. And as I understand it, a patient
3	who had been treated for a long time, a DNR was issued
4	something like three-and-a-half or four years in advance of
5	his death, and in fact, the fellow went back to work for a
6	year, you know, during that period.
7	Now there is another side to that story that I'm not
8	privy to, and HIPAA requirements keep the people who are
9	treating it from telling me it all, but regardless, I think
10	there ought to be some real judgment about the issuance of a
11	DNR, and it ought to be very clear that whatever has been
12	decided about the underlying condition that's going to
13	precipitate at death should not preclude being treated for
14	other things, and the patient ought to know that.
15	So I think that is a fair summary of the issues that
16	we've been involved in. Did I misspeak, Dr. Rust?
17	DR. RUST: (Indiscernible - away from mic)
18	SENATOR DYSON: For an old fisherman, right? All right.
19	Thank you.
20	COMMISSIONER BRANCO: Sorry. There might be one that I
21	didn't hear you articulate, and I may have just missed it.
22	But the medical futility of a patient who absolutely wants to
23	be resuscitated is still an issue in which physicians have the
24	authority to not cede to the patient's wishes.

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SENATOR DYSON: Yeah and that's an interesting one.

Dr.

1	Rhyneer, who I really appreciate, told us a couple stories of
2	a patient said, look, my sister who I haven't seen in 20 years
3	is due in on Thursday next, or you know, whatever. Do
4	everything you can to keep me going until we get an hour or so
5	together. And I think that, in that case, you ought to have
6	the you ought to understand not only the patient's
7	condition, but their wishes for that. And certainly, part of
8	the argument that we've had in here our discussions at
9	Providence is futility of it and the possibility of doing
10	further damage, but the guy that Dr. Rhyneer talked to me
11	about, he would have clearly said, go ahead and break my
12	wrist, whatever you've got to do. Get me enough time to see
13	my sister. And that's where the perhaps unusual but
14	extraordinary desires of the patient should prevail, if
15	possible. But you know, you guys took an oath, do no harm.
16	But I think we're saying, do no harm in dealing with the
17	underlying condition that's terminal, you know, but yeah.
18	So there should be a bit of tension on that, and it's
19	absolutely a judgment, not only yours, but the patient and/or
20	their surrogate.

CHAIR HURLBURT: Thank you very much for sharing this important aspect of the whole conversation that we're having during this meeting now. If we could go ahead, Ann Marie, and share your perspective?

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MS. NATALI: How often do I get to do that, shut you off?

SENATOR DYSON: Many wish they could.

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MS. NATALI: I am Ann Marie Natali. I'm the Director of Ethics for the Providence system in Alaska, and I very much appreciate being included on the community section of the panel because I do consider myself an advisor to anyone that accesses health care in the Providence system and that's really all of us. So I really appreciate that.

My role is really three-fold in responsibilities. I'm responsible for the ethics education of providers, which includes recognizing when an ethics conflict is occurring or is about to occur, and then also educating on what's an appropriate framework to analyze that conflict and come to some kind of hopeful resolution or recommendation. So an education piece. Obviously, an ethics consult piece, which I think everyone is familiar with the Ethics Committee and the role that they serve. But then also I have responsibilities to Providence as an organization. So I have some input into organizational ethics and policy and procedures to ensure that how we deliver health care really reflects our mission and values. So I really appreciate being on the community side.

I was reflecting during Dr. Ritchie's speech. Very insightful, and it reminded me of kind of the history that bioethics, as a discipline, has really traveled. Bioethics really erupted in the era of the late '60s/early '70s, where there was a clash with the technology that was available was

clashing with what we, as people, wanted for health care and how we saw ourselves and used the word existentialism, which is music to a philosopher's ears.

So that was really where bioethics really began, but bioethics, as an academic discipline, really does follow a lot of social and cultural trends as well, and what I mean by that is, if you look back to the original visions of the good doctor, the benevolent doctor, it was the doctor getting the call in the middle of the night, grabbing the bag, and jumping on the horse, and running to the family and that was the -- I call it the "Philosophy Principle of the Day." And bioethics can get very kind of lofty and theoretical. So I always try to describe it in practical terms, and I call it Principle Whack-a-Mole. It was the principle that popped up and whacked it to death.

So bioethics runs through those same trends, and I see us coming into a trend where autonomy has been the principle of the day, where it's been written to death and talked about, and some bioethics philosophers even refer to it as the era of the tyranny of autonomy, that that's the only thing that people talk about.

We're seeing an entrance of principles that talk about resource allocation and where does the value come into play.

So rather than the Whack-a-Mole concept of ethical principles,

I would advocate that we really need all of those principles,

at once, playing together. But I do want to mention in the tyranny of autonomy arena, I question sometimes, from a philosophical and a personal standpoint, if, as very independent, autonomous thinkers — and I think, as Alaskans, we take that independence to another level — if we don't contribute to or don't dance well with our own idea of end-of-life suffering and how we experience illness, that we need to balance that more, as a community, and look at health care as a community occurrence, not always from the autonomous standpoint that — and you know the talk. Do everything. It's available. I have to do it. So that's something to think about from a philosophical standpoint and also a personal standpoint, that autonomy is kind of the Whack-a-Mole theory of the day, and we need to really bring more things into consideration.

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I did like Dr. Ritchie's phrase "dignity-driven decision-making." I think that's a good phrase that we can all use when we talk about decision-making, especially at the end-of-life.

So my request, to both the Commission and to us as individuals, is two-fold. On more of a theoretical standpoint, I think we need more education and more comfortableness around challenging conversations and difficult conversations. I spend most of my day engaged in difficult conversations, and I see it, not as much as difficult or

uncomfortable, but as the most sacred conversation you can have with a patient or a family.

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So from the Commission's standpoint, I think we need more education, whether it's workshops or a task force to talk about how we make and help people become more comfortable with those types of discussions.

From a personal standpoint, I think, as health care leaders and ultimately, you know, members of the community, we all have a personal responsibility, too, to be the pebble in the pond that starts the conversation.

So I really challenge everyone here today to use this forum today as a segue to have that conversation, you know, maybe even tonight with your family and be that pebble and talk about, you know, I was at a meeting today and some interesting things came up, you know. Does everybody know what I want if something happens to me or after I -- you know, you can blame it on the Ethicist. You know, she brought up all these tricky topics.

But those are my two recommendations or requests from an ethicist's standpoint, that we need more education to make people comfortable with that conversation and that we all have a responsibility, as health care leaders, to be the pebble and start it ourselves. Thank you.

CHAIR HURLBURT: Thank you very much, Ann Marie. The last presentation is sharing some perspectives from the faith

community. Rick, I appreciate your being here, and go ahead.

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MR. BENJAMIN: I'm honored. Thank you for the invitation and including me. My grandparents came to Alaska as missionaries to Anchorage in 1946. I was born at the old Providence Hospital in Anchorage in 1956. My parents started Abbott Loop Church in 1959. I served as a pastor there for 30 years, and as a pastor, helped a lot of people at the end-of-life and did a lot of funerals, had a lot of experience. I do have a network of relationships with clergy people and faith leaders, interchurch, interfaith. In fact, I'm going to a pastors' lunch today. I'll have to miss lunch here.

Then three years ago, I went to work at Hope Community
Resources, which used to be called Hope Cottages. They
support people who experience developmental disabilities, and
they hired me to be their first ever Director of Spiritual
Wellness.

So I want to make this clear. Hope is not a faith-based organization. It's a secular organization supporting spirituality. Think about that for a minute. It's a very unique opportunity.

Part of my job at Hope is what we call celebrations of life for people who pass away. The mortality rate among people that experience developmental disability is raising. It's higher, but it's still -- am I getting that right? No. It's still lower than the general population. So we still

lose people all the time and that's part of my job at Hope, including grief support/grief recovery and so on.

Now two-and-a-half years ago, one of my bosses asked me to lead a task force at Hope to do end-of-life planning for the people that we support with IDD. And so we researched and found a document that's kind of like a simplified MOLST form, that includes simplified Advanced Directives appointing health care agents and so on, and we have now begun to do end-of-life planning for the 1,100 people that we support in nine regions of Alaska, and it's a real challenge.

I'm also the Chair of the Hope Ethics Committee for the agency.

On a personal level, my father, Dick Benjamin, 87 years old, experiences some disability. He can still drive, but he uses a walker. My mother, Carol Benjamin, she's 79. She's having some kind of dementia. It's probably Alzheimer's. She's lived in four places during the last 12 months and now she's at Prestige. She has a G-tube. She's non-verbal. Like my son said, it's like she's already gone. So End-of-Life Care has become very personal for me and my family.

The faith community, it says. Okay. No one person can speak for the faith community on this issue or any other issue. I'd be presumptuous and crazy to try to speak for the great, rich diversity of spirituality and faith traditions we have in Alaska, even in Anchorage. So that's kind of daunting

to be the person to speak on behalf of all of the above, but I really thought about it. I think I can give you some general principles that would be shared by virtually all faith traditions.

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Here they are. People are loved by God, created in the image of God, and worthy of love and respect. Life is precious and a precious gift from God and should be supported and protected. God really cares for the vulnerable and the weak among us, and He wants us to support and protect the vulnerable and the weak in our families, our communities, and our culture. But that care and compassion for the vulnerable shouldn't be condescending. I'm learning that care and compassion should be not about people, but with people in more of a relationship, like a friendship of care where there is actually a mutual benefit. It's not a one-sided relationship. I don't think a one-sided relationship is a relationship. And so I think most faith communities would say the way we care for the weak and vulnerable has to be mutual in a relationship. Older people, in particular, seniors, elders are a treasure, and we're losing them. And so they should be honored and listened to learned from. Those are just some, I think, general principles that faith traditions would agree on.

Now from the faith communities, from the faith community from our church in Anchorage from Hope, where I work -- again,

reminding you secular organization where I work now -- and for me, personally, I think I have one recommendation regarding End-of-Life Care and policy in Alaska. Don't leave out spirituality. So I'm very thankful that you didn't today and you included me today.

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Spirituality becomes even more important to people at the end of life, but it's always important. I want to say don't wait until the end of life to tack on spirituality at the very, very end. Oh, she's going to die. We better get somebody in here, like a priest or a chaplain or somebody. It's like all the rest of us have done all that we can do, so the very last person in the line is the faith person. I don't think that's appropriate. I really appreciate what Dr. Ritchie said about palliative care starting earlier on, including us, including the faith community.

I keep thinking about a TV show that I liked a lot called M.A.S.H. It was about that hospital in the Korean War, and there was one character, Father Mulcahy, the priest there, and the way he was regarded, it seemed like to me, was they liked him. He was sort of kind, pleasant, benign, but not very important until the very, very end. And then when they were going to die, get Father Mulcahy in here. And very often, people, like me, are made to feel like that, and I just submit to you that spirituality is more important than that, and it shouldn't just be tagged on a list of services, like physical,

mental, emotional, financial, oh yes, and spiritual. And it's always last in every list, by the way. And in fact, I'm last this morning and that's okay. I'm not complaining about that.

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Spirituality should be part of the team and part of the palliative care all the way through and also not tokenism, not like a box on a form that says, do you go to church, yes or no? Thank you, Ann Marie, for that phrase you just gave, a sacred conversation. I think talking about people's faith and religion and spirituality at the end-of-life is a sacred conversation, and it should go deeper. So there should be questions like, what is spirituality and faith for you? What does that mean to you? What is your own personal spirituality? Are you ready for the end of your life? What brings you fear? What brings you comfort? How can we honor your spirituality and your faith in your End-of-Life Care, so that care matches their personal spirituality?

Dr. Ritchie said, people want to strengthen relationships with loved ones at the end of life. Yes. So can we facilitate those very important last conversations? I love you. Thank you. Goodbye.

It doesn't cost much. I don't think it has to be a budget item. It doesn't have to cost anything. In fact, it doesn't even have to be doctors, nurses, and other medical professionals. Invite people, like me. There are a lot of us out there, clergy people, spiritual advisors, pastors,

priests, and this is what we do. So just get that in the plan. Get that in the policy. Get that in the team.

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Here at Providence now, we have an I.D. badge, which I really appreciate. Pastor, it says. Spiritual care. And the staff looks at this, and it gets me into the E.D., and it gets me into Adult Critical Care, and this hasn't been very long. And now they have three parking spaces that say "Clergy" here at Providence Hospital, and I really appreciate that. And it's actually making us feel, in those small ways, that we're not sort of a hindrance or an intrusion, but that we're actually part of the healing process, which we've always believed that we really are. And so thank you, Providence. It's just an example to include us in a meaningful way because we want to be part of the process.

If you're worried about spirituality in a pluralistic or diverse context, I can say, based on my three years at Hope, it can be done. You can support spirituality and all of its diversity in a very pluralistic environment with respect to everybody, including staff, because, if staff finds something spiritual that doesn't fit their spirituality, there can be accommodations made even there. We can respect separation of church and state. We can respect everybody's personal spirituality and still support everybody's personal spirituality. I would say don't be afraid of this; it can be done.

I'm thinking about tele-spirituality now, and of course, a sacred conversation seems like it needs to happen in person.

And these questions, I think, need to happen in person, but maybe there are ways that there can be spiritual supports through computer, internet technology. I'm going to think

about that one after today.

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That's my recommendation. Thanks for including me today.

Thanks for your attention. Thanks to all you Commissioners

for your public service. That's all.

CHAIR HURLBURT: Again, thank you very much. Initially, Dr. Ritchie, if you have some observations or comments or questions, and then if we have some time, we can open it up to the rest of the Commission.

DR. RITCHIE: Terrific insights. I have nothing to add.

COMMISSIONER CAMPBELL: We had several books to read this summer. It got marginally impinging on my fishing time, but - and it's a timely subject, and I thought it became -- toward the end of one of my sessions, this popped up in my mailbox in TIME magazine. It's my Joe Klein. He happens to be one of the editors. And I thought, is there a conspiracy going on between Deb and the Doctor and Joe Klein? Maybe. But anyway, I thought, this is a terrific way to introduce this subject to the general public. You can quibble with how he writes or his philosophy, but anyway, it's there. It's out there in a national publication.

UNIDENTIFIED MALE: What's the date of that?

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COMMISSIONER CAMPBELL: This was June 11, 2012.

COMMISSIONER ERICKSON: And can you mention the title of the article?

COMMISSIONER CAMPBELL: How to Die, and it's TIME magazine of June 11th, and it says -- the subtitle is, "What I Learned from the Last Days of My Mom and Dad." And it's -- he just tells the story. So I would recommend that to you, just as additional background and insight. Thanks.

CHAIR HURLBURT: Yes, Senator Dyson?

SENATOR DYSON: Thinking back to your question, is it Dr. Branco? Okay. All right. So your question was, you know, doing harm and so on, and in my view -- and I think Dr. Rust agrees with me -- that patient should have understood. You know, you say to the patient, look, you're on a downhill slide here, and you need to know that, because of our medical judgment, we will not do these extraordinary things to revive you that would cause you any harm and literally say, if you disagree, you know, with our medical judgment about that, we have an appeal process, and we could arrange for you to go somewhere else where they will jumpstart you and jump on you and so on and so forth, but we, in our medical judgment, will not do that. Those conversations, if happened ahead of time, there should be no real conflict. But that's a part of the things that Providence staff and I are -- we are completely in

agreement on.

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COMMISSIONER BRANCO: Thank you very much. This was an actual case in the E.R. I was phone ahead by family, saying that dad definitely wants to be resuscitated, and he's 95 years old with tissue paper skin, and all of his bones are like birds' bones, and we all knew and so we had -fortunately, I have an ethicist on staff, too, and we had a deep discussion as he came in and was watched carefully, medically, and he's competent. This is really his decision, and we spent an awful lot of time explaining to him that. And as graphic as it gets -- and this is very graphic -- is one minute of resuscitation ceding to your wishes, is three hours, at what point is it medically futile? It's actually medical futile before the chest compressions begin. And that's where we arrived in very difficult and very heated discussion in the E.R. with the physicians stepping into the back room in tears, saying I want to help this patient, but I don't want to harm them.

CHAIR HURLBURT: I'd like -- Ann Marie, I'd like to maybe ask you to share some perspective, particularly related to your role as an ethicist here in a Catholic hospital, where the tradition, I think the ethics in American medicine, American hospitals, particularly faith-related hospitals, has been to prolong life, to save life as a default judgment in the absence of an election for a Do Not Resuscitate choice by

a patient or a surrogate. Like everything else related to health care, that has been impacted on by the incredible cost now, and you could say that came out of a time that that wasn't as big a factor, but clearly, I think that's been our tradition to protect and prolong life, in the absence of a clear choice not to. Being in a faith-related hospital, what is your perspective on that?

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MS. NATALI: My sense, and specifically for a Catholic institution that has ethical and religious directives, is to avoid getting caught up in the words, in the loaded words and really focus on what's common among all health care providers, is really respecting the dignity of the human person. And if you look across all different types and styles of health care delivery, whether it's even in the U.S. or other places around the world, that really is the common denominator.

So when we talk about specific policies or procedures related to an institution, I try to steer the conversation to the meat of what the discussion is about, and to me, it really is about maintaining the sanctity and dignity of a person through the health care process, and it doesn't have to be a discussion about specific tenets or policies or procedures. It's kind of back to that conversation, the dignity-based decision-making.

It's kind of part of the role as an ethicist. It's kind of weeding through all of the red herrings and the rabbit

trails and getting to the meat of what the question is, and to me, it always kind of circles back to, how do we maintain the dignity of this person?

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COMMISSIONER DAVIDSON: I think one of the things we haven't talked about today is communicating for understanding, and I think we're really good at talking to people, but we're not necessarily good at making sure that people understand what we're saying. And I think that's true generally, but I think that's especially critical for what we're talking about now, and I think we should be careful about -- there are, sometimes, cultural references that are made that just make no sense to somebody who, for example, might be Yupik, and there are phrases that are used all the time that just confuse people, like when people say, well, in my opinion, but aren't you the one that's talking? Or when somebody says -- and we've heard this from our people that we work with, our patients. When we say things like, well, as a matter of fact, a Yupik person will hear "because the rest of the time, I'm not really telling you the truth." And so I think -- but they are really simple phrases I think we say a lot of times that confuse people unnecessarily.

For example, I just had a little experience. I turned to my friend over here because you kept saying -- I finally figured out you weren't guacamole; you were saying -- and I kept thinking, what do avocados have to do with this? And so

I leaned over to my new friend here, and I said, what does that mean because I didn't understand what you were talking about.

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But then the other thing that happens, I think it seems like there is this theory that the more educated a person becomes and the higher up they move into an organization or the higher their job status is elevated the longer and the more fanciful their words become, and we don't talk anymore. We converse, and we dialogue. And I think when you are talking to people for whom English may not be their first language, whether they're Yupik or whether they're Hmong or pick any other language, we make things unnecessarily challenging for them without even realizing what we're doing.

And we had an exercise recently in our organization where we said, you have a million dollars to be able to explain to somebody something, and every syllable costs you \$100,000, and oh, by the way, you still have to have money left over to provide care. And so gone were words like converse, dialogue, and back were words like talk and simple phrases. And so I would encourage people, as you're having talks with people, not conversations, that, when we're talking to people, we think we're communicating well, but remember to ask yourself, does this person look like they understand what I am saying? Have they heard, have they understood what I've said? Because a lot of times, I think, normally, people will nod and smile

Τ	very politely, and they haven't understood a thing that you've
2	said, and I think that's always we should always be
3	concerned about that, but we should especially pay attention
4	to that in conversations like this.
5	CHAIR HURLBURT: Thank you, Val, for that cogent comment.
6	It leaves to underlie of this here. I think we'll go ahead
7	and break for lunch. We'll reassemble at 12:30 and that will
8	be the time for the public comment period. So for those of
9	you who are on the phone listening in, we'll have a half-hour
10	break and then we'll open it up to anybody that has any
11	comments that you want to make, and we'll ask for that in the
12	beginning.
13	If we could there should be enough food for everybody,
14	but we'll ask that the Commission members and Dr. Ritchie
15	could go first and get their food, so we could come back and
16	be ready to reassemble, but there should be enough for
17	everybody in the room, based on past experience. Thank you.
18	11:58
19	(Off record)
20	(On record)
21	12:29
22	CHAIR HURLBURT: I think it's about 12:30, the time for
23	our public comment period.
24	(Pause)
25	CHAIR HURLBURT: We have several folks who signed up here

as being ready to testify. I think some of them were folks that were referring to -- participated in the panels, but I'll give anybody an opportunity, just to make sure there wasn't something else that came up there. Elizabeth Ripley? Oh, here you are. If you could introduce yourself, Elizabeth, and go ahead first, please? (Pause) CHAIR HURLBURT: Could you spell your last name for the

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transcriptionist here, please?

MS. RIPLEY: R-i-p-l-e-y. Elizabeth Ripley, and I'm the Executive Director of the MatSu Health Foundation. Health Foundation is a 501(c)(3) that shares ownership both in MatSu Regional Medical Center as well as MatSu Regional Home Care and Hospice, and we share governance of these entities, and we also make grants to improve the health of our community.

So thank you very much for highlighting End-of-Life Care today. I started my health care career in hospice, and I was fortunate to be part of a team of just extraordinary individuals that helped take Hospice of MatSu from a volunteer hospice to a department of Valley Hospital to the first Medicare-certified hospice in the state of Alaska. And it's maintained it's Medicare certification to this day and is under the name MatSu Regional Home Care and Hospice.

The last time I was here, I spoke regarding the need for

a state long-term care plan of which, obviously, end-of-life issues are a critical piece, and I talked about the fact that we had completed, in MatSu, a regional plan for the delivery of senior services and looked at the needs of seniors across the whole continuum of care. And interestingly, I have presented that plan, the findings and recommendations of that plan, in forums all over MatSu as well as in Anchorage, and on quite a number of occasions, people in the audience have brought euthanasia as a way to deal with the challenges presented by the plan, which says, to me, certainly, that we need to have a lot more dialogue about these end-of-life issues, and we really need to grapple with how we are going to ensure death with dignity to our rapidly aging population, and I just offer that to you as a personal reflection.

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So obviously, this is very critical work for the Commission; however, even though the last time I was here I spoke about the need for that long-term care plan and very much advocated for that, I did so prior to the Supreme Court ruling on the Affordable Care Act, and now, I think we have some more timely and pressing matters. The Governor has not made a decision regarding the Medicaid expansion, and while he has stated that the State won't create its own insurance exchange, there are still options to explore in terms of the State's relationship to the federal government and how the federal government will operate our exchange.

Commissioner Streur is working with the Department of
commence of the contract of th
Health and Social Services to analyze and really understand
who these new Medicare potential beneficiaries are and where
the State is already paying for them and where we're already
providing services, and we really applaud his leadership, and
we applaud this Commission's leadership in helping the
Legislature and the Governor really navigate through this
federal health reform, all these measures and really explore
ways to address cost and quality at the state level.

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But there are several time-critical ACA policy decisions that must be made between now and January 2014. This Commission, with its broad representation of providers, is likely the only sanctioned body in a position to assist the Commissioner, Governor, and Legislature in commissioning the analysis, in exploring how other states are implementing the Affordable Care Act because we're now we're moving on to this implementation phase, and really providing a forum for productive dialogue on these timely issues and ensuring that these critical implementation decisions are made based upon the best process and the best information. So I encourage you to really dedicate the remainder of 2012 and 2013 to planning toward this end. Thank you.

CHAIR HURLBURT: Thank you very much, Elizabeth. Yes, David?

COMMISSIONER MORGAN: I know that the reimbursement for

home health and hospice will change under the Affordability Care. I saw a CBO study that said, with those changes and reimbursement from Medicare, that 15% of the home health and hospices will probably go out of business because of this reimbursement issue, and I saw the same thing sort of happen to rural hospitals when I first started in this during the Carter Administration in the '70s. What impact will this change in Medicare reimbursement have on the hospice and home health agency you have in the MatSu?

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MS. RIPLEY: Well, I mean, whether you're looking at home care, hospice, or even the hospital piece, you know, hospitals, certainly in the nonprofit arena by the American Hospital Association, are being told, if you can't make a margin on Medicare patients, you're not going to have a future. So you know, our hospital is part of a system and is very efficient and that's part of this cost containment is driving efficiency so that you can maintain some kind of margin to recapitalize and invest in quality and services. And so I think we're at a very good position to do that in MatSu.

Our home care and hospice -- we've seen a lot of other home cares and hospices come through MatSu and try to make a go of it and not make it, and our home care and hospice has provided, you know, really top quality service and has maintained and has been very competitive. And because it is

part of a larger system -- I mean, we did enter into this LLC 1 2 partnership with Community Health Systems, an equity partner -- the resources that that larger system brings to bear in 3 4 terms of addressing quality and those efficiencies are pretty 5 phenomenal and so we're well-positioned to deal with those 6 challenges. Thank you, Elizabeth. Is Gwen Sensenig 7 CHAIR HURLBURT: here? 8

MS. SENSENIG: I am.

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CHAIR HURLBURT: If you could just spell your last name for the transcribers? We do have it on the list, but if we could get it that way.

MS. SENSENIG: I'm used to spelling my last name. Thank you. S-e-n-s-e-n-i-g. And I'm a Social Worker with Providence Hospice here in town in Anchorage, and I'm here today because of personal interest. I can't resist the opportunity to be a part of and listen to big picture solutions for problems that I hear people present to me in my work.

As I talk with patients in the hospice care setting, what I hear every single day is, why did we not know about you guys a lot earlier? And I think it's a big system thing. You know, I can't wait, actually, until I get to the point in my professional career where I can introduce myself at a party or a casual situation and say, I'm a Hospice Social Worker, and

people say, hey, that's great; what a tremendous opportunity you have to be a part of people as they write the script for their last days on earth. We do that for -- I'll stop rambling.

So what I've heard a lot of us -- I debated on whether to comment today because so much of what I wanted to say or point out has been said already, but it does, in my mind, seem somewhat of a simple solution that, if people say their end-of-life experiences improved in quality and it, indeed, is a lot less expensive for systems to maintain the burden, why are they not able to be in these hospice care situations much earlier? And the things that we are hear people say are they thought it was for when you were actively dying, maybe had days left to live or that all a hospice care team would do would be to administer the morphine drip.

Despite our 25 years of hospice care services, we're still there, and we've already discussed, here in this setting today, I think the education that has to happen and kind of the discussion among the continuum of care providers from oncologists to hospital folks to hospice care settings.

Currently in Anchorage, our average length of stay on hospice care is 20 days and that mirrors national averages.

So we could be caring for folks a lot longer, and they want us to be doing that. Forty percent nationally -- according to the National Hospice Care and Palliative Care Organization,

40% of our U.S. population will die in hospice care, and I don't think we're at those levels here in Alaska. It's an underutilized service.

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We also have had -- what your comments were, just preceding mine, were disturbing about Medicare and Medicaid cutting their reimbursement to hospice care. I'm sure our Administrator would be able to speak more clearly to those numbers, but I think about 70% to 80% of the patients that we serve, their bills are paid by Medicare and Medicaid, an additional maybe 10% by private insurance, and then there is some charity payment as well. Many of the private insurances follow suit with what Medicare and Medicaid are doing. So if they're not reimbursing that, it becomes a problem.

Some of the private insurances now do -- excuse me.

Medicaid and Medicare will provide for unlimited time in hospice as long as you continue to meet the medical criteria, so it can go beyond that six months. Some private insurances that we talk to folks, they will only cover 20 days of hospice care. We've encountered that through the last several years. So that places huge burdens back. When we ask people, where are you if you're not in hospice care, they say we have a lot of concerns about whether we're doing this right. We're back in the emergency room, and they are utilizing services that are a lot more expensive.

One of the things that I thought of -- sometimes, good

1	solutions come from crazy ideas. In most cases, that's not
2	true with me, but one of the things that I was thinking is
3	that, at the beginning of care, we offer or at the
4	beginning of life, we offer this fabulous children's health
5	insurance for those who are not insured or underinsured. At
6	Providence Hospice, we happen to see a population that mostly
7	has insurance, and I am guessing there are many, many people
8	out there who we do not see at all. What about, as a state,
9	offering something similar to the children's health insurance
10	plan that is subsidized by the state and the federal
11	government that provides for home-based health care services
12	similar to hospice care end stages? It could save some money.
13	I'll leave that up to brains much more capable than mine.
14	Thank you.
15	CHAIR HURLBURT: Thank you for your comments, and I think
16	I picked up, particularly, on your comment about your

CHAIR HURLBURT: Thank you for your comments, and I think

-- I picked up, particularly, on your comment about your

average length of stay of 20 days because we do get concerned

about the six-month limitations, but the reality, in my

experience, is that the average length of stay is so short and

it's so often a missed opportunity to get people into the

wonderful support services that hospice provides. So I think

that's an important perspective to share with us.

MS. SENSENIG: Thank you.

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UNIDENTIFIED FEMALE: (Indiscernible - away from mic)

CHAIR HURLBURT: Karen Perdue, the CEO of ASHNHA?

MS. PERDUE: Hello, Commission Members. I'm Karen

Perdue, CEO and President of Alaska State Hospital and Nursing

Home Association. Sometimes, it sounds like a cough, ASHNHA,

but ASHNHA beginning its 60th year this next year. So we've

been around since before statehood, representing the needs of

hospitals and nursing homes.

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The last time I was here testifying, I talked a lot about data and data transparency, and I want you to know that work continues on our hospital discharge data system, trying to work with our members to report timely and completely and also we stand ready to work with the Commission on future projects on data and data transparency. We think that's very, very important.

I did also want to comment on this particular time in history that I feel that we all know is fairly unusual in that we're at a time of great change, but we're also at a time of continued uncertainty in the health care industry. And our members are responsible for keeping the doors open and serving patients and so there is only so much speculation that they want to engage in about what's going to happen in Congress or what's going to happen over the next year or two, but we do have some concerns that we need to start laying out some of the options and doing the contingency planning that is necessary for a whole host of changes that we may see beginning as soon as November or December.

And just to kind of go over some of those things, the sequestration is currently planned for critical access hospitals to take a 2% reduction. That could be very impactful in the Medicare reimbursement. The ACA, itself, has plans for large reductions for hospitals. We've estimated that to be about \$24 to \$30 million in the out years, and those were planned as part of a way to pay for access. We await the disproportionate share rule making, which is one of the ways that we fund some of our critical behavioral health emergency response in the state. On the Medicaid side and the Medicare side, we see -- we're planning -- we're being told that the Medicare reductions (indiscernible - voice lowered) are up to 75%. So we're waiting to see what that rule making is.

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We have a large interest in the Medicaid program, as we all do, and we know that the Governor is -- we applaud what the Governor and the Commissioner have done, which is to take the time to really study what this means for Alaska. The numbers that we see are somewhere between 35,000 and 55,000 individuals who today, more than likely, do not have health coverage, who are certainly coming into our emergency rooms and needing care from providers, who probably don't have insurance today. So that is a big decision, I've heard, over the five-year period, about a \$2 billion decision for Alaska of which the State would pay about 6% of the cost.

So we are very -- you know, we're trying to keep track of all the change that's occurring, and we welcome public dialogue that we can engage in. We don't have actuaries on our staff. We don't have the ability to create our own information. And so we really enjoy and find fruitful the ability to work with the Commission, the Department, anyone who can provide us with more information.

We know that, on November 16th of this year, the State has to determine if they want to become involved in an exchange and so that's another deadline.

annual conference each year, and our conference is going to be in Anchorage this year. We don't often meet in Anchorage, but we are this year, September 6th and 7th, and I invite any one of you who is interested to attend to contact me, and we're going to have some excellent presentations. We're expecting the former governor of Kansas, who is the head of the American Health Care Association. He focuses on long-term care and assisted living, leads the nation's advocacy on those issues. He'll be here. We have an excellent set of panels of local experts and some real in-depth looks at new health care systems and how they're evolving. So lots of policy discussions for those of you who can't get enough here at the Commission meeting. Thank you very much.

CHAIR HURLBURT: Thank you, Karen. Mark Regan?

MR. REGAN: Commissioners, thank you for inviting public comment. My name is Mark Regan, spelled R-e-g-a-n for the transcript. I'm the Legal Director for the Disability Law Center here in Anchorage. I wanted to say a couple of quick things about hospice and then a couple of other things about the Commission's agenda for the next six months or so.

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This is to say good things about hospice. When my dad was near the end of his life, he had made very careful plans in Juneau as to how it was going to go. He had bought a combination couch and chair that he was going to stay in, in the living room, and yet, he was uncomfortable. signed up for hospice about four weeks before his death, the hospice nurse came and said, you don't seem to be comfortable, and he finally admitted that that was true, and the hospice nurse said, well, two things. First, your oxygen stats are off and so we'd like to give you an oxygen tank, and the second thing is your couch looks uncomfortable to me and so we'd like to bring in a hospital bed. So they brought in the hospital bed. They brought in the oxygen tank, and the last four weeks of my dad's life were greatly improved, not because he hadn't, you know, thought very carefully about what he was going to do, but because he didn't understand -- and we didn't understand -- the very simple things that could be done to make somebody's life easier. So I'd like to say thanks to Hospice and Home Care of Juneau. It's a few years since then,

but it's a very valuable thing. And we're always going to remember, but there are families in this position who don't know this, and they're only going to find out if hospice is there to help.

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As far as your agenda goes, I'm glad you're talking about end-of-life issues (indiscernible - recording interference).

On the agenda, your plan for every meeting of this Commission is tracking prior year recommendations and federal reform.

What's happened with the Supreme Court decision at the end of June is that new things have intruded on what your plans for what to cover. The Supreme Court, for better or worse, has decided that the State has the opportunity to opt out of the Medicaid expansion. That is an enormously important decision for people with disabilities and for other people who haven't been able to get health coverage for working families. It's a decision that, in my view, has to be made by a combination of the Governor's office and the Legislature because we have a statute that says we take all mandatory Medicaid categories automatically, and so when Medicaid rules change, we take those categories. If the State wants to opt out, it's not simply a matter for the Governor's office to decide. It's a matter for the Legislature to decide, which, in terms of your agenda, means this: If you have recommendations to make on this incredibly important issue, those recommendations will be valuable to the

Legislature at any time before it concludes its session next year. So you have time to collect data on this. You have time to make recommendations on this, and I'd urge that you do that.

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There is even time to make recommendations and to examine what to do with respect to the health insurance exchanges.

The Governor made a decision not to pursue a state-based exchange, but it's still possible for the State to tell the federal government on November 16th that it would like to have a partnership of some kind with the federal government, and this is an area on which I think that the Administration could probably use your help and guidance, and there's time, whether at the October meeting or a little later, to provide it because my guess would be the State isn't going to say anything until after the election and until November 16th.

Thank you very much.

CHAIR HURLBURT: Thank you, Mark. Jesse Collens?

MS. COLLENS: (Indiscernible - away from mic)

CHAIR HURLBURT: Yes.

MS. COLLENS: Hi, I'm Joann Collens, not Jesse. He'll be here next. And I think I need to apologize, but I'm not going to all the way. I was told that you folks were meeting today, and I didn't realize that it was about people checking out hospice. So can you just twist your minds, just for the ten minutes that Jesse and I may both be up here with you? I'm

going to try to make it really brief.

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I've been researching this system since my son fell on his bicycle three years ago. He is a quadriplegic on a vent, and the State has approved 24-hour nursing for this person, but can't provide it because there is only one agency in the whole state, and they, through detail that I don't need to get into right now, say they can't provide that much service. If we're lucky, we may get three shifts out of 14 possibly by the middle of next month.

I've been caring for my son since May 25th with my 22-year old son because personal care assistants and respite people cannot poke his finger. He is diabetic. They can't give him insulin. They can't give him medication, and they can't manage his trach.

So I've been doing a lot of research. He is part of a waiver program, and when I talked to people in SDS, everybody has said, wow. They said, talk to CMS, and I said to CMS, can you help me, and they said, talk to your state. So then I called DHSS and talked to and wrote letters to different people, and they said, talk to SDS. So we've been dancing since April 3rd with no solution, no help. I have the number of something that talks about specialized private duty nursing, and when I asked the person who said, have you tried CMS -- I've already said to my boss -- I said yes. Have a great day.

1	We're in trouble, you guys. It's not only Jesse. It's
2	people. God forbid your child falls over on his bike and you
3	or don't have insurance. We're not proud that he's in this
4	insurance. He's a Type I diabetic. He couldn't afford
5	insurance. He had to buy his insulin. That was when he
6	turned 16. I flew up here, and I've left my life. I was
7	about ready to teach sustainable living and education and
8	food. Now I've chosen to be a mom. I'm not asking you to be
9	sorry. I'm just asking you to help me be creative. I've
10	envisioned other possibilities. I don't know who to talk to.
11	If any of you know, our email address is written on that piece
12	of paper. Please, please help us.
13	When I've called the state legislature, the three
14	conversations were, I'm going to a workshop in D.C. in July.
15	I've called him twice, and he hasn't called me back. When I

When I've called the state legislature, the three conversations were, I'm going to a workshop in D.C. in July. I've called him twice, and he hasn't called me back. When I talked to both -- and I'm sorry. I'm pretty new up here. I don't know everybody's last names, but to Lisa in Mark's office, they said, have you talked to your state reps? Oh, okay, but they're all telling me it's the federal government guideline. You get my picture. I'm not going to keep going on. Just please help me. Thank you.

CHAIR HURLBURT: How will it be best for -- I'm sorry -- use those down there.

(Pause)

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MR. COLLENS: My name is Jesse Collens, C-o-l-l-e-n-s,

and that was my mother who spoke earlier. So I had a bicycle accident three years ago. I have to rely on Medicaid and Medicare. I've been approved for 24-hour nursing, seven days a week by Medicaid, and I also use the Alaska Medicaid Waiver System, the Choice Waiver System, and with the one agency that I had used for the specialized duty nursing for the past two years, they could not provide full services. So now I'm hoping to get three 12-hour shifts a week, like my mom said, out of 14 a week.

My brother had to leave his life in California to come up and take care of me because, when I went and spoke to the Senior Disability Services, they said, well, wait; do you have more family and friends because you're just going to have to rely on your family and friends to live independently in my own home. I had lived in St. Elias for about two-and-a-half months, and going from being 21 and having a very independent life to going to a hospital and now having a taste of what it's like to live in my own home and independent, being sent to an adult ventilator facility, which does not exist in the state of Alaska, would be sending me to Washington, and it just — that is not living independently, to me.

I guess there is a lack of ability that the private duty nursing industry can actually do here in Alaska, and I just want everyone to consider options when it comes to the specialized duty -- I'm sorry -- specialized duty nursing.

1	They seem to the nurses have their own insurance and
2	billing I.D.s, yet they cannot bill Medicare directly, and I
3	think that that's a big mistake. That's my biggest problem.
4	I think that's pretty much all I have to say right now, so
5	thank you.
6	CHAIR HURLBURT: Thank you, Jesse. Thank you for coming.
7	MR. COLLENS: Yep.
8	CHAIR HURLBURT: Is there anybody else in the room who
9	wanted to testify? How about online? Do we have folks online
10	who would like to share comments? Anybody online, anybody on
11	the phone? Okay. Thank you very much. We're about five
12	minutes after one. Why don't we go ahead and take our
13	scheduled break, about 15 minutes, and come back about 20
14	after one then?
15	1:03
16	(Off record)
17	(On record)
18	1:22
19	CHAIR HURLBURT: I wonder, could we gather together again
20	for our discussion time?
21	(Pause)
22	CHAIR HURLBURT: Well, I tell folks that the ones who are
23	on time are the ones who get the that's when we distribute
24	the bonus checks.
25	(Pause)

CHAIR HURLBURT: As we get back together again, again, I'd like to express appreciation to Deb for putting this program and panel together, including finding Dr. Ritchie and contacting her, giving her background that she needed and coming up, and getting the two Reactor Panels that we had. I don't think you could have a better session dealing with this topic than Deb put together, so many thanks. Do you want to say anything as we start out, Deb?

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COMMISSIONER ERICKSON: Well, I just -- why don't I talk, just briefly, about our process generally for the afternoon and then see if we have questions, does that sound like a plan? We're missing half of our members, but that's okay. That's okay. So I can just babble about process for a few minutes while we wait for them to come back and then you guys get to do most of the talking for the rest of the afternoon, how's that, after listening so attentively all morning.

So our process for follow-up on End-of-Life Care issues is -- after that real intense learning session and all of the reading materials you all have had, we're going to spend a little time now just in brainstorming, giving you a chance to throw out, initially, any major thoughts that you would want to characterize as a major finding around End-of-Life Care issues in Alaska that we'll capture in just a brainstorming session. We're not doing any wordsmithing at all this afternoon. And then we'll spend a little time capturing

preliminary ideas you might have related to potential
recommendations we might develop. And then after we do that,
we have time on our agenda to look through some additional
documents, and I have slides in our Meeting Discussion Guide
PowerPoint that you have with you. It's one of the new
handouts that you got this morning. It looks like this, and
it's online as well, for folks who might be listening on the
phone. And we'll talk a little bit more about our plans for
the rest of the year, and I've captured, from previous
brainstorming sessions and learning sessions at our earlier
meetings in March and June, the major concepts related to
findings for those things that we were just studying, that we
weren't developing recommendations about, but then the one
area where we are going to work towards having recommendations
in our 2012 report that we have studied so far, telehealth,
the two major ideas that came out related to recommendations
or areas of recommendations related to telehealth that we
discussed at our last meeting.

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So I thought we could revisit those points, and we're not going to do any wordsmithing. I'm hoping we don't do any wordsmithing today. I just want to see if you have any ideas related to general concepts that you think are either missing or wrong, from the major ideas that I've laid out in those slides.

We will revisit both -- we'll take some time again when

we're fresh in the morning because I know this was a pretty
exhausting series of sessions here this morning. So after
your brains have had a chance to process overnight and we come
back fresh and rested in the morning, we'll revisit the ideas
from our preliminary brainstorming this afternoon on End-of-
Life Care and also we can go back and look at any of those.
If any of you have any additional ideas related to some of
these other areas where we've captured findings around
malpractice reform, behavioral health, recommendations related
to telehealth, those are some of the other things we'll look
at later this afternoon, and we'll have time to work on those
again tomorrow morning. And then we'll have a series of
updates tomorrow morning, and we'll finish the morning off
with a presentation on a new statewide planning initiative
that's just launching, health planning initiative, public
health planning, and a conversation about how their work is
aligned with ours and how we're going to make sure it stays
linked and aligned and we're not off duplicating each other's
work or stepping on each other's toes. So that's our plans
for the rest of the day.

Well, let's just brainstorm about End-of-Life Care for a while and then we can go into a little more detail about our plans for the rest of the year a little bit later, unless anybody has questions about either what we're doing this afternoon and tomorrow or the rest of the year. Pat and then

Colonel Harrell and then Dave?

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COMMISSIONER BRANCO: Thank you very much. I was caught by Dr. Ritchie's comment about the value equation. We're all very familiar with it, and the cost element though, and especially when we're talking end-of-life, one of the often-used phrases is 80% of the health care dollars are spent in the last two years of life. However, the flaw in that is, are we able to predict when those last two years will be coming, and therefore, effectively reduce the costs associated?

I think it's incumbent on us to start to work towards a paradigm in which we're able to predict in -- I love that word, that care thing that begins with a "P" that I can't pronounce -- palliative care starting earlier in diagnosis of a seriously ill patient and starting to get the data and information on the costs of health care earlier in that process rather than our typical approach of waiting until the final ER visit through our EMS system. I think we'll be able to start to change that value equation in a meaningful way and a positive and productive way, as people approach the end of their lives, each of us.

COMMISSIONER HARRELL: So when I hear discussion, like this morning -- there are lumpers and splitters. I'm a lumper, so I begin to try to pull things together and so I heard three major themes, communication being the foundational one, in my mind, of Dr. Ritchie's talk, but within

communication, subsets of that would be public service type announcements, particularly focused on telling a story, much like the current tobacco use ads are right now that are on television personifying an issue in terms of being able to educate the public, changing mindsets related to hospice care, itself, to make the populus aware of where they can go to additional information.

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The second communication piece, which really is still education is the whole telemedicine piece and how you can train extenders and educate patients and families, not only as to what's available to them, but also how they can engage in the care of their family member that's in the end-of-life stages.

And lastly, communication as it relates to training, particularly of medical staff, either on a truly primary medical education level, which would involve curriculum and how you're going to inject that into the different venues that we train professionals here in the state of Alaska, but beyond that, the larger issue -- and being a physician, I can say it -- is the stick-in-the-mud that physicians tend to be about not jumping onboard with this kind of thing. One of the comments was made that symposiums are offered and very few Anchorage physicians took part in that. So physicians tend to be the weakest link in this issue in terms of being able to be involved in these kinds of processes and changing behaviors.

So the second piece, after communication and education, would be standardization. I heard two major standardization issues. One is standardization of forms that are used throughout the state in terms of making it simpler for folks to be able to engage in palliative care type actions. And then the second standardization would involve the palliative care formulary and so being very direct in terms of standardizing the formulary across the state.

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And the last piece would be incentivizing. We've talked about that before here, and it's, how do you incentivize the use of palliative care and hospice care? How do you incentivize providers? Particularly when the first panel was up, you have three different models of care delivery. You've got private hospitals. You've got the Consortium. And in the private model, you actually have two different versions of that. So how do you incentivize the physician, the care provider who happens to work for a hospital, but has a primary practice to engage in this kind of thing? And so I'm very interested in what Jeff has to say and where we might move, and Dave, in terms of how you incentivize folks who really have no vested interest, other than altruism, to engage in this, and you can't trust human nature to be altruistic all the time.

So those are the three main issues that I heard and some subsets that are, at least, percolating in my brain in terms

of how you would go about setting policy. 1 2 COMMISSIONER ERICKSON: Colonel Harrell, did I capture your three major themes pretty close? 3 Sure. I would say the -- well, 4 COMMISSIONER HARRELL: 5 the telemedicine piece under communication wouldn't 6 necessarily be telemedicine. Therefore, the clinical 7 education -- clinician education, you're good there. It's the third bullet, third sub-bullet. That wouldn't necessarily 8 9 just be telemedicine. That would be the use of symposiums and 10 other forums to be able to educate the provider staff. It's 11 been my experience -- and again, since I'm a physician, I can 12 say it -- that nurses and medical technicians come along with 13 this much faster. Physicians are trained to be islands, and 14 they don't like teams. And so you've got to convince them 15 that there is value added in being a part of a team delivery, 16 in being able to make this happen. The rest of it looks like, 17 pretty well, what it said. 18 COMMISSIONER ERICKSON: David, you were next. Oh, I'm 19 sorry. What? 20 UNIDENTIFIED MALE: (Indiscernible - away from mic) 21 COMMISSIONER ERICKSON: Thank you. 2.2 COMMISSIONER MORGAN: I just wanted to -- first, my 23 comments were basically dealing with reimbursement, which is 24 incentives, by the way. 25 One correction. When I was talking, I was referring to

the Medicare reductions in home health and hospice. the individuals testifying started doing Medicaid/Medicare reductions. As far as I know, there isn't any Medicaid In fact, our Medicaid reimbursement rates, feereduction. for-service, and other modalities are actually usually higher than the Medicare rates, but I'm concerned about that, especially the CVO study in the home health and hospice arena. We have so little of it that the Medicare parts are going to be hit pretty hard on the reimbursement side, which I still can't figure that out, honestly. You're keeping people out of hospitals and other formats to do that. And though I'm not a -- I do cost reports for a home health agency, certified Medicare home. I think you'll find that there is a little bit of that going on in some home health agencies, which is okay. You work with what you've got to get done what you need to get done.

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The one part I didn't understand, and probably the physicians understand it much better, is a hospice house or facility, and I know, from what I heard, that we don't have one in the state, but I don't know if we need to add that to part of our process to, at least, look at it to see what's — is the reason simply we don't have people to put in it or management to run or reimbursement to fund it or simply don't have enough patients that want to do it to go in it? So I guess those are my only comments in this one. Thank you.

COMMISSIONER HARRELL: Deb, could I add one more thing? In terms of where you focus, particularly the communication piece and the incentivizing, resources are what they are and so I think one of the places you could focus on would be the critical nodes of transition. If you're going to educate and you're going to incentivize, I think you need to identify a finite number of places that you're going to focus resources at, and probably, in my mind, the biggest bang for the buck is going to be those transition nodes because that's where people fall down. They don't know what's available. They don't know how to transition their care. So educating the populace and the health care community on those transition nodes would be a place to focus when resources are limited.

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COMMISSIONER STINSON: I thought some of the points that Annie Holt made -- how they do the forms in Utah -- were very good. What the State could do -- we've become much more Internet-friendly, since that time. I don't know if there would be a site where, perhaps, people could declare on a state of Alaska site -- they could have the forms that they could carry around with them, but if they made their wishes known in some kind of secure way that hospitals or other providers could access, that would be something that, if you're picking up somebody in the middle of nowhere or in the middle Anchorage, they could be accessing -- see if they have -- if they are registered on the Alaska state site, and if

they are, then, if they don't happen to have the little form on them, you'll know what their wishes are by the time they hit the ER or maybe even by the time they get picked up for transport. And if we have new technology, we ought to use it.

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I'm also in agreement with the other points that were made. One of the -- having a hospice house -- I have an uncle who is a Canadian family practitioner, and we often get into very prolonged discussions. He's been on the National Health Care Board for Canada, and they have a much different way of looking at a lot of things than Americans. So I try not to talk too long with him, but on hospice house, he is an absolute true believer. He says it is validated. Hospice care is something that more than pays for itself. It is a big part of the Canadian health care system, and I believe him in that regard.

COMMISSIONER KELLER: Yeah. I was thinking -- and maybe you can correct me, if I've forgotten something, but the emphasis on palliative care being early in the process of dealing with this, did we include that in the patient-centered medical home model? Did we talk about that at all? It seems like, to me.....

COMMISSIONER ERICKSON: We did not.

COMMISSIONER KELLER:that we might want to back up and do that, and specifically in that arena, maybe what Dr. Benjamin pointed, you know, the spiritual aspect, because, you

know, the State -- we're trying to deal with issues, you know, life's deepest questions here, you know, and this here PCMH, if we went back and maybe thought about that a little bit, it captured my attention when he said this may be free, you know, if you contact the right people. And I was just thinking, you know, that our -- as a Commission, we might be able to reach out or initiate some contact, something, you know, to get this going so that the communication is, in fact, with the communities, and you know, the families, and the churches, and that kind of thing. I don't have anything specific in mind, but it seems like there is something we ought to be able to do to steer it that way.

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COMMISSIONER CAMPBELL: Well, I was caught by some TV ads about grannie going over the cliff, and we've heard about (indiscernible - voice lowered) in regard to all of this reformation that's taking place. So I think we ought to be very, very cautious about the semantics and how we use these terms so that the Commission and our recommendations don't get too politicized as they hit the Governor's office and the Legislature next year because that's the worst thing that could happen to our endeavors, in my mind, is if somebody grabs a hold of who might be an enemy of one facet of this particular topic that we're talking about, and I think we've got to be really, really careful, so just a caution.

COMMISSIONER STINSON: I totally agree with Keith. If

we're going to make recommendations for hospice care or a hospice house, it has to go along with the education that Colonel Harrell brought up, where we — there has to be a public awareness campaign that this is not denying people care. This is not preventing care. This doesn't mean, if they are in a DNR status and they break their leg, they don't get a cast; they don't get treated. They do. But to the average person on the street, and particularly if people use sound bytes, that could come out very wrong. And so it would have to be part of a larger educational campaign.

CHAIR HURLBURT: Emily?

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COMMISSIONER ENNIS: Dr. Ritchie spoke about the integration of palliative care, and I asked her to clarify that afterwards, and she did refer to the community-based services that already provide support in home to seniors as one example of the need for combining the care of the hospice services and services that exist.

Caregivers and employees that work for the community-based services work in the family homes with people with serious illness and also with terminal illness, and yet, they don't see their work or their responsibilities having to do with this kind of care, not that they're opposed to it. They just don't receive the training, and I think that would be my recommendation for another area of education and a way to get the information out to families so that you have a worker in

the home. They have the connection with the hospice program nearby or wherever it's located, but there is information to be shared, but there also would be strategies and support that the respite worker or their chore worker or the adult care center employee could be employing in their own service provision. So the concept of integrative care, I think, expands farther than just the community-based services we already have in place for seniors, but clearly should be looked into how far we can extend the education and understanding.

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COMMISSIONER HIPPLER: Thank you. There were certain aspects of this discussion that reminded me of our discussions on behavioral health, specifically a demand for a service that is not currently being supplied.

In our discussions on behavioral health, one of the points or one of the findings was primary care physicians should be providing, at least, some level of behavioral care. And today, additionally, one of the recommendations was, well, primary care -- or excuse me -- palliative care should begin at the primary care level. That may be the most costeffective way to do this, but we should keep in mind that training primary care physicians and expecting them to provide -- or training general primary care physicians to provide palliative care and expecting them to provide that does come with a cost. We have scarce resources. We can only do so

much, and if we demand more from the same people who are not providing that service right now, costs will go up.

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COMMISSIONER URATA: One of the things that, I think, would be important for education and probably will help change things a little bit is to stop using the term "Do Not Resuscitate" and use the term "Allow Natural Death." If you're going to allow natural death, if you break your leg, you're going to get fixed. It has nothing to do with resuscitation. But if you're dying, you're going to be allowed to die. And if your heart stops, you're dead, so to speak. So you know, that might be something that might help people understand what we're all trying to say.

(Pause - background discussion away from mic)

COMMISSIONER DAVIS: So maybe I didn't learn how to spell it, but I can tell Deb how to spell it in a minute. A couple of things. I thought this was a fascinating discussion, at least for me, because I didn't know much about it coming in, even though my mom was in hospice and my stepmom was in hospice, and it was a wonderful experience for both of them.

But the distinction that -- the big distinction -- so I'm lumping for a minute -- is that palliative care is not hospice, but hospice is part of palliative care, but it's a much bigger and broader and that was an a-ha for me. So somehow, I think we need to capture that in there.

To Keith's point about not stepping in the political

thorny bushes, I think some of the ways that care was described today were wonderful about that. Sorry. Just a second. I took too many notes, so I'm confusing myself.

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(Indiscernible - voice lowered) talked about how hospice is not hastening death; it's not trying to slow death. It is providing comfort and compassionate care in the natural death and that was just, I think, a really clear way to understand what's really being talked about here.

One thing that I can't speak to, Colonel Harrell, is the reimbursement, and I really want to know more about that. Emily asked me, are there (indiscernible - voice lowered) codes for that, you know, for this work because there a lot of great work going, but some it, you know, I'm not sure how it gets characterized. Maybe you have some insight into this, Dr. Urata, but you know, I'd like to understand better how things do get billed in an insurance environment, where it's not just -- you know, outside of the hospice arena, how do things get billed and how do they get paid for and how are they covered because it seems, to me, that -- and we didn't get a lot of data, but we got some that shows that this is cost-effective, and to Pat's point about the end-of-life and the cost, you don't know when the last two years are, but if you're beginning palliative care at the time of diagnosis, it doesn't really matter because you're getting people what they want. Their dignity is being respected. Their outcomes are

described, as we saw from Dr. Ritchie earlier, in a much more positive way than without, and then you just naturally transition through the stages of the progression of the illness.

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So there is a lot here. I, again, don't feel qualified to make much in the way of finding, other than I would like to understand more about how it's paid for because that could help get to the incentives piece. And it looks like Kim Poppe-Smart is not here any longer, but I know -- oh, are you here, Kim?

I was just going to say one last thing. With respect to your point about the patient-centered medical home, Deb -- or someone put it in there -- it's that the State Medicaid is working on their model and their request for people to be interested in that, and if there is a way maybe to think about incorporating that into the specifications for those pilots, that could be a way to maybe kick start this a little bit. Thank you.

COMMISSIONER HARRELL: So a couple of other follow-up thoughts. I really, really enjoyed Virginia Palmer's two quotes that somehow, I think, really framed the emotion of what we're talking about in terms of ultimate recommendations. One was, "put the hope back in." That was a phenomenally good commentary regarding how we interact with our patients. And the second was, "I'm a person, not a battlefield." That

speaks to Westernized medicine, and I think, in terms of how we frame our recommendations, keeping that emotion engaged, I think, would be quite useful.

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Additionally, as we look towards formulating some sort of a policy recommendation, this would be my own personal axe to grind. I would certainly want language to be of a permissive legislative permissive versus a restrictive legislative language. Whenever you start getting involved with a provider-patient relationship, I think we are better off providing permissive language that sets a playing field or a foundation versus restrictive language in how we couch the terminology and the recommendations.

And then lastly, back again to resources and the question that I was trying to get to with Dr. Ritchie is that, ultimately, whatever recommendations this body comes up with, we're going to have to deal with the fact that there is not money to go around for everything. So we're going to have to pick and choose where we would recommend investment and that goes to whether you focus your efforts into the health care community of professionals or you focus your efforts into community-based practices that are non-professionals, if you will, but the ancillary support. That may be a legitimate discussion to have in terms of where your bang for your buck is.

COMMISSIONER STINSON: Not to mention spirituality last -

- right, Rick? So make sure it's on the end of this slide, Deb. I thought some of the things that Rick Benjamin shared with us were important, perhaps, to be included and that was kind of a commonality across people of faith or spirituality that, you know, you could take a view that people are loved by God, they're made in His image, they should be loved and respected -- and therefore, should be loved and respected and that is the basis, the center of palliative care. everything else kind of can flow from that solid center. And so I think it would be important to capture that, as well as his comments about it's not, you know, rushing in at the last moment, but if -- you know, this is the center of our beings, and no matter where people live spiritually, then it's important that it be at the center of any program that's touching on the ends of our -- not program, but care that's touching on the ends of our lives. Thanks.

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COMMISSIONER ENNIS: Just to touch on Colonel Harrell's comment about community services, there was a provider here earlier, administrator of a fairly large assisted living home here in Anchorage, and I asked her what training or services they provided in palliative care, and she said really minimal to none. And if you think about the fact that we've been talking a lot about individuals who have families and the care for the family, the involvement of the family in planning the end-of-life, we do need to remember there are a large number

of people who are living in assisted living homes that are really pretty much on their own, have no family involved. No one comes to visit. Nobody is really checking on the quality of their end-of-life, except the assisted living home administrator and some minimally paid employees. And I do believe we need to address this as well, in terms of education and support. Maybe some incentives that would encourage our assisted living homes to take a better. I think they do a good job. I think they're doing the best the job they can, but at least, one has offered, you know, that there is no approach or training in this area, and I think there should be.

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COMMISSIONER URATA: I'd like to go back to sort of the areas of care -- I want to emphasize the areas of care of that palliative and hospice and carry-out and that's in four. And to start out with, of course, one is spiritual, and the majority of patients are religious. So it's related to their faith. But there are a few, a minority, who do not have a faith. They still have spiritual problems and spiritual pain. So we need to make sure we don't forget them.

The other is social health and that's community and family, particularly. Psychological health, which has to do with their depression, anxiety, their fears, and there are therapies for that.

And of course, finally and lastly, physical health, which

1 is the medical part, and you treat that with -- you know, 2 treat the pain and discomfort with medications. COMMISSIONER ERICKSON: What did you mention between 3 4 spiritual and psychological? 5 COMMISSIONER URATA: Social health, which is, you know, 6 your family, your friends, your community. So those are the 7 four components that I see as important that palliative care and hospice care provide or should provide. 8 9 COMMISSIONER STINSON: I agree with Bob, and I just 10 wanted to, more or less, make a comment, not something for 11 inclusion. 12 When they've done studies and they've looked at states 13 that do have euthanasia laws, if you control the pain, almost 14 nobody opts for euthanasia. It makes it almost irrelevant. 15 And so pain control at the end of life, with the other 16 support, is really what people need. 17 CHAIR HURLBURT: There are a couple of areas that some 18 states have mandated as a part of their physician licensure 19 process in terms of continuing education. 20 One is pain management because it's such a challenge 21 nationally, but the other is palliative care, recognizing that 2.2 there is often not enough -- with our focus on acute issues,

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there is not enough recognition of the importance of that, and

I think that's the kind of thing that the State Medical Board

probably deals with, and generally, I'm not a big proponent of

a lot of mandates, but it's something that's probably worthy of consideration and discussion.

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In terms of the cost issues that have been raised a couple times here, my sense is that so much of what -- when we've talked about a specific area, so many of the requests and suggestions that come to us really are things that will increase costs and then we're faced with the dilemma that Tom referred to, that we can't just keep getting a bigger and bigger pie. But I believe, in this area, there is opportunity to enhance the value equation to do better without increasing The -- my experience -- and I may be just limited by the situations that I was in. As Dr. Ritchie commented, there is a daily fee for Medicare, for folks going into hospice. And then I believe, in addition to that, if you have an acute intervening problem, say somebody with terminal cancer and they develop a bladder infection and you're going to treat the bladder infection, I believe that's in addition -- do you know, Steve, is that correct, or Bob? Yes, please. Yeah?

MS. DOOLEY: Yeah. We do.....

COMMISSIONER ERICKSON: Pat, could you come to a microphone?

MS. DOOLEY: If you're under a Medicare-certified hospice, that is a per diem rate, and we do provide medication for pain and symptom management. So if you have a bladder infection or upper respiratory infection or something that's

1 making you uncomfortable, or frankly, if it's making your 2 family uncomfortable even if it's not making you uncomfortable, we will treat it. 3 4 CHAIR HURLBURT: And that generates reimbursement for 5 that treatment, over and above your per diem? 6 MS. DOOLEY: No. 7 CHAIR HURLBURT: It doesn't; okay. 8 MS. DOOLEY: No. There -- no. We get a per diem rate, 9 and we provide all of those services, including the 10 bereavement for that. 11 COMMISSIONER URATA: Can I give an example? 12 CHAIR HURLBURT: Yes. 13 COMMISSIONER URATA: So if the patient goes to the 14 emergency room because they have something and they did not 15 call the hospice nurse and they get admitted to the hospital, 16 the hospice, the Medicare-certified hospice, is obligated to 17 The patient has no fees under the Medicare pay those fees. 18 hospice program, but that can bankrupt the hospice program, 19 unless they have a lot of patients that would be able to 20 absorb the expense, but you only get \$150 a day. And if your 21 average census is seven days or -- I think ours is around 14 2.2 days. You know, we're just barely afloat if somebody -- and 23 we go into big problems if they end up in the hospital.

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the patient and family about what to do in an acute situation.

So it's really important for communication to occur with

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They need to talk to the hospice nurse.

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MS. DOOLEY: Just as a clarification as well, if you're in hospice and you are having -- you know, your symptoms are getting worse or you're really, really uncomfortable and you do call the hospice nurse, the nurse will come over, and 99% of the time, we can take care of people's symptoms at home. They do not need to go to the hospital. If hospice decides that you do need to go to the hospital, that we can't manage it at home, then we do cover the cost, but if you decide -- if you're on hospice and you decide you're going to go to the hospital and check in and get additional treatment for your cancer without letting us know, then you would be on the hook for that cost. So I just wanted to clarify that little bit.

MS. DECOURTNEY: One of the biggest things about a true palliative care....

THE COURT REPORTER: Please state your name.

MS. DECOURTNEY: Oh, Christine DeCourtney. One of the big things about hospice or palliative care is cost avoidance and that is where the savings and that's from Medivacs, ER, hospital admissions, and ICU admissions. And you know, if we talk -- we need to talk about two different things. There is the Medicare hospices, but then there are the other systems and those are like the State Medicaid, which this would be -- you know, what Medivacs cost the State Medicaid and so forth. It's cost avoidance, which is a big piece of providing

appropriate palliative care. 1 2 CHAIR HURLBURT: Thank you. COMMISSIONER DAVIS: Deb, can we capture those specific 3 4 areas of cost avoidance, please? So transports, admissions, 5 ER visits, and ICU days, specifically. Thank you. 6 COMMISSIONER HARRELL: Just an additional comment. It's 7 very interesting that the cost avoidances here, of course, dovetail very nicely with the same things as telemedicine. 8 You're avoiding all those things. It's just not sexy to talk 9 10 about them because its cost avoidance. So it's hard to 11 quantify, but telemedicine and where we're moving in the 12 palliative care actually end up accomplishing the same goal. 13 (Pause) 14 COMMISSIONER ERICKSON: This is brainstorming. We can say sex while we're brainstorming. 15 16 CHAIR HURLBURT: Val? 17 COMMISSIONER DAVIDSON: So the other part -- I think it 18 was mentioned earlier, but I just want to make sure that it's 19 adequately covered -- is the piece about educating the public 20 and families early in the process. I mean, it's that whole campaign, just beyond educating the providers whether they're 21 2.2 community health aides or doctors or whatever. 23 And there was also a concern that somebody raised about, 24 well, you're asking doctors to do more and more and more, and

community health aides have the same concern, but they have a

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bigger problem because they're also the first responders, and it would be like a Providence surgeon here driving out to a car accident, saving the person there, and following them back to the hospital and continuing to provide their care.

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So I think the -- I think there are things that we can do that we've had success in the community health aide program by extending care beyond -- so for example, just as a surgeon specializes in surgery, we don't require them to do the -- be the primary care doctor. We don't require them to be the, you know, et cetera, et cetera, et cetera. We can do things that will allow people to maybe use their time more efficiently, so that, if we set it up properly, people can provide services that are within the scope of their practice, thereby freeing up the time of somebody who receives a different kind of training to be able to allow them to have more time to do that. I don't think I said that very clearly, but....

COMMISSIONER ERICKSON: Are you suggesting that the training for community health aides be expanded, scope of practice for community health aides?

COMMISSIONER DAVIDSON: I guess what I'm talking about is, just as a community -- we have community health aides. We have behavioral health aides. We have dental health aides. Maybe we need palliative health aides. Pick a fancier name. I'm not going to say sexy, but....

COMMISSIONER BRANCO: I've been chewing a lot on the home

health topic from several perspectives. First, I have a home health agency, and it's heavily subsidized by the hospital. It doesn't make money, but it's one of the most costeffective, cost-avoidance programs we've got. It keeps people well and healthy in their home, eases them through. often participate in palliative care, and our volunteer hospice is run side-by-side with our home health agency. so looking ahead at health care reform and the reductions coming in reimbursement to home health agencies, I'm just struggling with this terrible moment, and I'm actually regretting speaking out loud for fear my home health agency is listening in or will read this in the future and wonder why I'm contemplating or would have to consider closing part of what I do or subsidizing it more heavily at an increased cost to the hospital and distribute it over the payer mix. just a -- it's daunting.

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But I have one more piece and then I'll let you get to it, and it's readmission piece. Penalized for readmissions when, in my view and the view of a few others, we consider it, often, a good catch by our home health agency for patients who are discharged to home health, see that acute phase, come back because of a chronic or serious illness and that home health nurse catches it. They're readmitted. They recover again. I just can't fathom being penalized for that appropriate level of medicine. So there; I pontificated for a moment.

CHAIR HURLBURT: Well, I think, if you are going to send a patient home right after cataract surgery instead of log rolling them for two weeks in a bed in a hospital or you're going to send newborns home at 24 hours or 48 hours, recognizing that you're not going to pick up neonatal jaundice and that most can be treated with bili lights at home, but some are going to have to come back, that means that a part of a totally appropriate system, to deliver value means that some people are going to come back and be admitted, and if that is not a part of your plan, you're not serving your patients well, I don't think.

COMMISSIONER BRANCO: So exactly the point. I'm going to be incentivized to be a strict guardian of the gate and say, hell, no; you won't come back because you're going to affect my reimbursement rate, and I'm going to suffer a penalty. So doctor, under no condition, can you readmit that patient, unless you prove to me and everybody else that it's an appropriate readmission.

CHAIR HURLBURT: David?

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COMMISSIONER MORGAN: As we were talking, I was trying to get my mind around this, too, and the one thing we haven't mentioned -- and I still, in my own mind -- my father says I have one of the finest minds of the 16th Century, who, by the way, is 87 and still practicing full-time dentistry, if that - so is ACOs -- that the ACO legislation might be the escape

hatch in this problem because then you're being (indiscernible - recording interference) like a (indiscernible - voice lowered) almost, with some insurance and emphasis on primary care, that then dealing and managing through this, as long as you're optimizing the best care, the appropriate care, it -- and I haven't actually (indiscernible - voice lowered) this out on a (indiscernible - voice lowered), but I think that might be something, especially in what you're talking about, and I'm not speaking for tribes. I'm speaking for community health centers, but community health centers look at the tribal system, and in many of the rural parts of the state, the community health center is also the tribal health center. And in the case where I worked for five years, we were under contract as the health department for the borough at the same time.

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So basically, I think we're going to -- someone, someplace in all of this is going to have to step back and look at formalizing ACOs that then can bridge this and process this through. It still may not -- it still may be all messed up in a way, where you've got contradicting forces inside your own business plan, but I think we do need -- I don't think -- we may not necessarily need to do an in-depth, contractual study, but I think we might want to, at least, look or have staff kind of see, well, do ACOs take care of this, or at least, mitigate it for the non-tribal groups in this?

In my mind -- like I said, I'm not speaking for tribes, tribes are virtually ACOs, in a way, and that's how they justify home health agencies and other programs, like this.

They utilize them, do the reimbursement, and they can compute, because they have the status, how many bed days they saved, and sometimes, they go back, but still, it's a net positive and that's how they justify the subsidy. I'm assuming that's what you do, too, like every year or six months, say, hey, we saved 500 bed days, which we wouldn't have been able to bill for or something. So that cost, minus the subsidy, we're still good, that kind of stuff.

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But like I said, I'm like you. I'm going, like, well, you know, I've looked at this and read the regs, and how are they going to implement it? We still don't know. It's still a jump ball. I mean, that's the way I see it. What do you think, Patrick?

COMMISSIONER BRANCO: I think you're right on the money. And again, it is a push-me-pull-you dialogue in my own brain that gives me a headache often, but I really think we'll land on fair footing. Staff-Model HMO concept, the ACOs -- I'm more familiar. I'm an old military guy. That is the largest health care system in the world, and it's a Staff-Model HMO. It works well. There are incentives in order to keep non-profitable services available in the community because of a balance of net savings or cost avoidance, not by shifting the

cost to the payers for the other services that we do strictly on volume. So it's a smart model as well.

COMMISSIONER MORGAN: As we all know, I had a small part of the VA contract, but one of my -- I was sort of given an assignment to work on a section. Guess what? Home health, respite, and developing those. I was looking at -- excuse me -- how the VA does that, and it's very interesting, and maybe I'll, tomorrow, make photocopies and hand it out. It could be -- the VA system has the most flexible, you know, take what you got, make it work kind of system, especially in these community-based programs, which you were saying, and I had no idea. And I'm looking at their outpatient respite and their daycare, and they call it home health aide homemaker, which retros me back a long time, but probably me and Val are the only two that remember homemaker services.

So we might be able to -- you remember that? I still have them. Oh, okay. That the -- maybe we can amalgamate, at least, some options in all this. Hey, I don't know, but enough. I've beat this horse until it's bloody. So thanks, Patrick.

(Pause)

COMMISSIONER BRANCO: It's okay if we have silence for a couple minutes every once in a while, while we're brainstorming, especially after David talks. And Patrick, if you're going to say sexy again, you have to turn your mic on.

(Pause)

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COMMISSIONER ENNIS: I appreciated the discussion by Ann Marie on ethics in this area, and as we were talking education and public information, I would recommend that we also be sure that's included.

COMMISSIONER DAVIS: Is that with or without guacamole?

UNIDENTIFIED MALE: The fact of the matter is that, in my opinion....

(Pause)

CHAIR HURLBURT: So we heard -- Pat talked about the dilemma that you face, where your right hand and your left are separated, and you have a program that is saving money globally, but doesn't meet your needs as the administrator of the system, the way money comes to you in pockets, and we have David's comments, and then looking at the former employer that Jeff and I share in common, Group Health in Seattle, where, basically, you were on a capitated rate -- you had your enrollees paying their fees, and the system -- because it was the right thing to do, but the system elected to have a hospice program, basically home-based. It didn't serve all of the patients -- talked about a hospice house here -- but there were 400,000 enrollees in the Puget Sound area, and we had 12 hospice beds that we used for respite beds for the occasional person who wanted to die in an institution rather than dying at home. The program was very well -- I couldn't go in and

read the testimonies from families of people who had been enrolled without getting tears in my eyes. It was really impressive.

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But because of the kind of thing that David was describing -- and it was an ACO -- they were able to elect that and make that choice. We probably cannot affect what CMS does, but in the state -- you know, as we've talked repeatedly, the State's big buyer -- there are more constraints on Medicaid, probably on what CMS allows or doesn't allow, but with state employees and retirees. There are the union trusts involved, but there may be more room for looking at that, and I think that Becky Hultberg, who has come and met with us, who is the Commissioner of Administration, is -- just, you know, the costs are eating us up so much, as a state, that she is willing to look innovatively and perhaps, at least for the share of the patients that are coming from the state, that perhaps the State could address your dilemma for that segment of those patients, so that you're not in a Hobson's choice of being forced to make a bad decision either way that you go, that it should be a win/win, and it's kind of a lose/lose right now. And I don't know if that's something that we might want to think about encouraging the State to look at.

COMMISSIONER BRANCO: I had another topic to talk about and wondering if Ann Marie can shake her head up and down or

side-to-side, if does Providence have a "No Dies Alone"
program? Yes. Okay. Good. There is a nod up and down.
This is for those who don't know, this is a program that
has a spiritual basis, a social basis, but is also a respite
basis, and it for our hospital, it's run by the volunteer
hospice group and our hospital chaplain, but the concept came
from an ICU nurse who checked on a patient and said, I'll be
back in just a minute. He said, would you stay with me for a
little while? And she said, I'll be back in just a moment.
And she went, and a moment in ICU can last for quite a while,
and she came back, and he died alone, no family. It's a
powerful impact, and she felt it to the core of her being as a
caregiver and vowed that she would never see another patient
die alone. And so we often have family members in attendance
around-the-clock in hospice care, especially near the end, and
it's very wearing. As Jesse described, having shift coverage
three shifts out of 14 possible, it's very likely he'll be
unattended by skilled nursing at any point in his life, not
even just at the end.

But the concept of being there for the person and providing that respite to the family in which a volunteer group, whether they're hospital staff or community members, to be there with a dying person in those last few hours, but still allowing the family time to go sleep, recover, come back, and do their vigil as appropriate. It's not really the

purview of what we're deciding today, but I think it's one of those moments that we ought to recognize that not all end-of-life is tragic or tearful. There are happy moments, and there are blessed sendings. And so I offer it just as a piece of information and one we ought to try to spread more often to more places and get your community involved in the dying process. I think it adds to the community education piece as well. Death is terrifying until you've experienced a good death.

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And I was fortunate enough -- at 19 years old, the nurses on the night shift were really tired of me hanging around. I had cleaned every stainless steel device on the unit, and they said, Pat, why don't you go down and sit in room 14 with Admiral Jones? That's a made up name, so you can't look it up. We expect he is going to die tonight. So I thought, oh, I can't. I've got something else to do, but they talked me into it by issuing an order.

And so I went down there, and I sat with him, and I didn't know what to do, and the room was dark, and I watched him breath in and out and breath in and out slowly, and he slept peacefully. And about four -- and he reached his hand out at one point, and I held his hand. After about four hours, I realized I have to go to the bathroom. Oh, I can't. I've got this special, sacred duty I'm doing here. I thought, if I go out, he'll die when I'm gone. But as I was waiting

and thinking about my bladder, I lost track, and he was no longer breathing in and out. He just breathed out. And his hand never relaxed. It was just the most peaceful passing. And ever since that day, I've never been afraid of death, ever, because it can be peaceful and reassuring. All right. I'm done.

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MS. STEPHENS: Anchorage had a community group of people that were interested in a hospice house probably ten or 15 years ago that came together to see, could we have a hospice house in Anchorage? And it basically came down to finances and no one organization willing to do that. Hospice of Anchorage just doesn't have the financial resources to sustain a hospice house. I've seen them all over the country. They're often very gorgeous, a place one would like to be to die, where families are comfortable and the individual is comfortable and well taken care of. They're usually set up in a home-like setting.

That being said, it's never been one of my priorities. I think that hospice care in people's homes is still the preferred way to go, and I realize that there are some people that don't have a home and a hospice house might be necessary and needed. In Anchorage, we tend to do that in assisted living facilities. We have many assisted living facilities that have — that caregivers have become very good at End-of-Life Care, and with hospice support either from Prov Hospice

or Hospice of Anchorage, those people die comfortably with good care.

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I worry that a hospice house puts a tremendous amount of resources in one place, that ten, 12, 15, probably maximum 20 people are able to access it at any one time, and there are a lot more people than that that need our care. I worry that we -- expertise is not distributed. It gets to one place rather than meaning the responsibility of the whole community to take care of end-of-life well.

So I just wanted to share with you sort of the pros and cons of what I've seen.

CHAIR HURLBURT: Thank you. Any other comments? We're going to come back in the morning and discuss this some more after some time for reflection and maybe kind of focus things down and narrow them and look at them again.

COMMISSIONER ERICKSON: I think one other thing that I might try to capture here, too, is the comment that Val had made at the end of our panel presentations. I don't think it came up again during this conversation, so I didn't capture it on the slides. But Dr. Ritchie made a point of mentioning to me afterwards on the break how important it is and how much they emphasize it in their training of their physicians and their palliative care team staff, the importance of creating understanding and not just communicating, and they actually teach certain methods for how to do that, how to ensure that

1	there has been understanding on the part of the patient and
2	the family when they're talking to each other. So I'll
3	capture that in a bullet, too.
4	CHAIR HURLBURT: The last item that we're going to have
5	today is review and discussion of the Commission documents.
6	Do you want to take a little break again before we do that?
7	So it's 2:30. So let's start at quarter until three.
8	2:28
9	(Off record)
10	(On record)
11	2:45
12	CHAIR HURLBURT: Can we come back together again?
13	COMMISSIONER ERICKSON: We're going to get started again
14	in just a minute, if everybody can come back to the table,
15	please?
16	CHAIR HURLBURT: If you turn to page 11 on the handout
17	you received today, Deb has that up on the screen.
18	COMMISSIONER ERICKSON: Are we ready to get started
19	again?
20	CHAIR HURLBURT: Yeah. Let's go ahead.
21	COMMISSIONER ERICKSON: Commissioner Morgan?
22	(Pause - background discussion)
23	COMMISSIONER ERICKSON: Now we and you do all have
24	this our Discussion Guide PowerPoint in your packets, and
25	we're on slide 11 in your handout. We added some slides just

now in our brainstorming discussion, but just real quickly, I wanted to review our -- this was our agenda for 2012, for this calendar year. We have all of the different areas where we've made recommendations in the past, and we're spending some time this year going back and revisiting any status -- progress made related to those various areas, and we spent a little bit of time at each meeting on two or three of those. So we're kind of ticking through them as we go through the year, and we'll touch on a few of those again tomorrow morning.

But we have four areas where we're continuing to study the current system, and we're not necessarily going to come up with recommendations related to those areas, but at the end of the year, we'll have a set of findings and some information related to those different areas and that's the cost to pharmaceuticals in Alaska, behavioral health care system, the malpractice environment, and more specifically, the effect of the malpractice reforms over the past couple decades. And then we're continuing to track implementation of federal health care reform.

And the four areas for strategies we're studying for the development of new recommendations are telehealth, enhancing the employer's role in health and health care, improving quality and choice and End-of-Life Care, and reducing government regulation.

And I have, on our next slide, a summary of our schedule

for the full calendar year, including what we've done so far this year, and our plans for the remainder of the year. And so now at this point in August, our focus, even kind of our meetings, we're falling out in different theme areas. So this was -- our discussion today really has been about quality of care. We'll be more focused a little more specifically on cost at our next meeting, and we have arranged for John Torinus, who is the author of The Company That Solved Health Care, which was your other book that you received for reading, is coming, and we've partnered with Commonwealth North and are going to have Mr. Torinus actually speak at a luncheon that will be a Commonwealth North forum, and we'll have about 150 or so community business leaders joining us for that luncheon, and we'll have a series of presentation more specific to Alaska following that.

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But we also will be hearing about two of the studies that we have underway at that next meeting, and we'll be spending time at that meeting working from drafts that you'll receive between now and then of our findings and recommendations, to date, and refining those. We will do a little bit more wordsmithing at that meeting on those documents and then release those for public comment. November will be the public comment period. We'll have all our draft Finding and Recommendation Statements out, and we will reconvene, for a day, on December 10th to review all of the public comments,

similar process to what we used last year, and make final changes to our Finding and Recommendation Statements that will then go to the Governor and the Legislature on January 15th.

So just kind of a summary of where we're at with our overall process.

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I wanted to take a couple minutes to fill you in on the status of the two contracts that we have in place right now and see if you have any questions or any suggestions for those.

One of those -- this was actually a recommendation. For those of you who are newer, folks in the room who don't know that much about the Commission's work, we had studied the need for an All-Payer Claims Database for Alaska for supporting a number of different improvement areas, everything from transparency, public reporting transparency to use by clinicians for clinical quality improvement, and for payers as a data source for coming up with and supporting new payment strategies, just a few examples of how All-Payer Claims Databases are used.

And so this was one area -- the Commission actually made a recommendation to itself. We were concerned that, if a recommendation was made to the government that the government study it, they wouldn't do it, so that we should just do it ourselves. So we have a contract in place now. We had a competitive process, actually got five very good proposals

from across the country. This group, Friedman Health Care, is actually based out of Massachusetts, run by a physician, and I think the co-partner in the organization is a former Medicaid Director, and they administer All-Payer Claims Databases for a number of other states and are engaged in health care analytics in a variety of other initiatives and projects.

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So these folks are onboard now, and we've been working with them, and we're working towards holding a series of inperson -- they'll have a Site Review Team come up to Alaska and spend a week here, the week of September 17th, to hold a series of Stakeholder Focus Group meetings because we're really trying to -- I mean, not just do a feasibility study, whether it's feasible to have an All-Payer Claims Database or a needs assessment, whether we need one or not, those will be a couple of the questions, but we really need to understand if we can make the business case for it. Is this something that we can develop and will be used and will be supportable and sustainable? And so working with various stakeholders is an important part of that.

The plan that we've come up with so far is to have three large focus groups, but then in addition to that, there will be a whole series of much smaller groups and individual interviews that they'll conduct, and they'll have some time after that week to do some follow-up phone interviews for folks they don't catch during the week of September 17th.

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Right now, we're looking at organizing into three different groups, one with payers -- so this is one area I'd particularly like your feedback, if you have any suggestions. The payers group -- you had a question? Yes?

COMMISSIONER CAMPBELL: I do. The groups that you're interviewing, stakeholders, do you anticipate, if someone was -- any one of them -- I don't have an idea even who you're going to interview, but do you have -- if somebody is vehemently opposed, one of these user groups, to even studying this, would they necessarily have a veto power over whether it moves ahead or not, the study?

COMMISSIONER ERICKSON: Whether the study moves forward?

COMMISSIONER CAMPBELL: Yeah. If you have somebody, a

major stakeholder who just absolutely would not and just lays
their body across the tracks, whether they would participate
or not?

COMMISSIONER ERICKSON: I cannot imagine that scenario.

I don't think so. We're looking at having a final report,
written report in final form by the end of November. So
whatever -- we won't, ultimately, have any control over what's
done with that report, but it will be a public report. And
I'm assuming we'll make some recommendations, based on what
we're learning from these folks.

COMMISSIONER KELLER: Follow-up on that, Deb. Are these going to be public meetings or these are confidential meetings

between the study group and the stakeholders?

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COMMISSIONER ERICKSON: These -- I think they'll be public meetings. I'm not sure how other stakeholder meetings have been organized earlier this year around different issues, not that this isn't controversial, but I don't think it is -- what I'm imagining is inviting -- we have lists of 30 to 40 people for each of these three categories, and we're still fleshing it out a little bit. And I'm not imagining advertising in the paper that we're holding these meetings, on one hand.

On the other hand, I'm imagining the folks will circulate the invitations that they're getting and that we met have additional people show up, and we're not going to kick them out of the room. And if somebody wants to invite somebody to come with them, that will be fine. We're also going to provide teleconference lines for folks who aren't in Anchorage. The face-to-face meetings will be here in Anchorage. But the three major groups that will be the larger focus groups are broader categories.

So for the Payers group, we're inviting all of the major insurers, the ten leading health insurance companies in our state, third-party administrator company leaders, insurance brokers, some of the larger employers that have self-insured plans, just as some examples, and also looking at inviting the leaders of some of the associations that would represent small

business, chambers of commerce, for example. So just employers in general and also union trusts.

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For the Provider/Stakeholder group, hospitals, physician groups, dentists, pharmacists, so just major associations as well as some of the individuals who are leaders from those different sectors.

And then for the Public Health and Community Planners and Researchers, that list has gotten pretty long, folks from the University from a number of different research centers, some of our more senior epidemiologists and staff with the Division of Public Health that work with community planning and with epidemiology, and some other community-based groups that get more actively involved in planning, like the United Way, just as one example, and also the planning boards, like the Mental Health Board and the Mental Health Trust, and those folks will be invited, along with that group as well.

But then in addition to that, we have a growing list of individuals and then small groups of individuals who we want to make sure have an opportunity to talk privately in a separate interview with the consultants. Just for example, we'll invite the Hospital Association leadership because they administer the Hospital Discharge Database, which isn't the same, and they won't necessarily be linked directly in any way, if we were to move forward with an All-Payer Claims Database, but it's the closest, most similar type of data

system that we have in the state. So we want to make sure that they're actively engaged. A core team of folks involved with the development of the Health Information Exchange and also the folks who are -- a separate group, the folks who are engaged in making policy decisions about the Health Benefits Exchange as well as the Health Insurance Exchange, even though we're not going to administer that as a state entity, since that decision has been made, but two of the questions we've asked in the scope of work for this project, in addition to just assessing the business case, whether we can make a business case for this or not, are what opportunities there might be to align an All-Payer Claims Database in the state with a Health Insurance Exchange, with a Health Information Exchange, and with a Hospital Discharge Database? So that's another set of questions that we've asked related to this system.

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One other thing that I've asked our consultants to do is to set up an Internet-based, online form where people can submit written comments, uninvited and confidential. So anybody else, either who is in one of these meetings and feels as though they can't be perfectly frank or if they've been perfectly frank and want to make sure their message didn't get missed and don't necessarily want the Commission or the Department to know who was making the comments, they'll have an opportunity to provide confidential comments to the

consultants.

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And so in addition to the stakeholder meetings and interviews, they're doing a variety of other information-gathering activities as well. So does anybody have any other questions or comments?

Our plan is they will be here in Anchorage in person, again, on October 11th and will make a presentation on their preliminary findings to all of you in your next meeting, and based on feedback from you on additional work they'll do over the subsequent month, they'll finalize a draft report for us to review and then we'll have the final report from them by the end of November. Any questions or comments?

The one other contract we have in place now is with Milliman again, the same company that did our last cost analysis for us. This was a competitive bid process again. We actually sent -- made sure the RFP went out to quite a few different organizations, but Milliman was the winning bid for the cost comparison. It will be very similar to the one that was done for hospital and physician services, comparing Alaska between those same states that we did the comparison for those other services, looking at difference in reimbursement levels for different payer categories between our states and then also identifying the drivers of the cost differences.

And they also will be at our meeting on October 11th.

Actually, I think I just asked them to be available

telephonically, but they will be presenting their draft findings at that point and then we'll have the final report from them at the end of October. So does anybody have any questions about plans for these two studies?

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Hearing none, what I mentioned this morning, for those areas that we've studied so far, I had compiled just the main points that I'm imagining will get crafted into finding statements for the malpractice reform. I captured some thoughts from Linda Hall's presentation on health insurance regulation as well, but that's going to get pulled into a broader piece on health care regulation, and then also findings from the behavioral health system presentation we had earlier in the year, and then just some preliminary findings and also recommendations for the telehealth area.

So I thought we could go through those briefly this afternoon. If there is anything that jumps out at you as significantly missing or off base, we can tweak it and revisit it again tomorrow morning, but then a couple weeks in advance of our November meeting, you'll have the more thorough write up on each of these with the Finding and Recommendation Statements that we'll spend time at our November -- October meeting. I'm sorry; it's Keith's fault. Our October meeting. We'll spend more time at our October meeting refining these and finalizing them for public comment. Yes?

COMMISSIONER ENNIS: Two of the public testimony speakers

spoke about the Affordable Care Act and the recent Supreme
Court decision, and if I heard correctly, they felt that it
might be the -- oh, responsibility is maybe too strong a word,
but certainly in the purview of the Commission to take a
little greater involvement in the analysis and the
implications for the state of Alaska in regard to Medicaid
expansion and the Health Care Exchange, and I know we have, as
a Commission, really only participated in updates, but I did
want to remark on those two public testimonies and just see
what you thought or what the Commission members thought in
relation to this recent precedent-setting decision.

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COMMISSIONER DAVIDSON: So are we going to be getting any kind of actuarial data from -- or any kind of information similar to what the cost is for some of this other work that's happening about the economic impact of Medicaid expansion to the state of Alaska and sort of what the rollout plan is and how that might impact our state?

COMMISSIONER ERICKSON: Well, the Commission is going to have a report from Commissioner Streur tomorrow on the Health Insurance Exchange and the Medicaid expansion decisions that the State is going to be making, but the Commission doesn't have additional analysis beyond what we've done so far, in our Mark Foster study that was done a couple years ago. I could make available to you the -- I mean, it's available on the Web; I could send the link out -- actuarial study that was

done by the firm that just completed the study on the Insurance Exchange.

COMMISSIONER DAVIDSON: I guess I was hoping for a "moral of the story" version.

COMMISSIONER ERICKSON: David?

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COMMISSIONER MORGAN: Actually, it's more than that.

There is over 100 pages talking about it, going through the requirements, and then there is an actuary study, which I printed off and looked at. It was about 160 pages. So that's the exchange. I think economic impact analysis, plus -- and this will warm the cockles of Wes' heart -- the actual impact cost on the State would be a major undertaking, and I'm sure it's being done, but I don't know if the Commission has the resources or the actuarial people to do that. I mean, that's a big -- that's a lot of maturation, I think.

COMMISSIONER KELLER: It may not be as specific as we like, but there are several studies out there that have compared all the states and the costs. The numbers are available, so you just go online and find it pretty easy.

COMMISSIONER ERICKSON: And they vary, and we have -- I mean, there are a number of different national organizations that have developed estimates. We have our initial estimates from Mark Foster, and we have the more recent Health Benefit Exchange actuarials.

I don't know if it will be helpful to revisit the

decision that we made early on not to participate in reviewing and commenting on the Affordable Care Act, was based on a number of -- at least, a couple of issues.

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One was, at least initially, before the Supreme Court decision, since this Commission was focused on high level policy recommendations, we were recommending, basically, to the State what needed to be done, but not getting into the operational details on how it should be done, and the sorts of policy that were set in the Affordable Care Act were the "what's," and any recommendations beyond that really would be getting into the "how."

What changed with the Supreme Court decision -- before the Supreme Court decision, there really weren't any -- except for grant programs that were getting into doing some demonstration projects -- and we're going to learn about one of those from Pat tomorrow -- there weren't recommendations related to actually implementing policy really to be made because the Affordable Care Act directed that these provisions were going to be implemented, and to the extent the State had some decision-making, the decision-making was whether the State was going to do it or leave it to the federal government to do it, and if the State was going to do it, how was the State going to do it.

What changed with the Supreme Court decision now is we do have a very significant policy decision that the State will be

making regarding whether or not to expand the Medicaid program.

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One of the other -- I mean, we really were trying to keep the Commission from getting too politicized and focus on what we could do in terms of establishing state policy that would address the affordability and quality of -- and we were trying to be focused, as much as possible, on medical care because there are boards responsible for -- and organizations responsible for doing planning in other areas for behavioral health, long-term care services, those sorts of things, where there is no other body focused specifically on planning for improved quality and cost and access to medical services.

Pat, yes?

COMMISSIONER BRANCO: I remember that discussion really well, and the pretty strict avoidance of getting into the political arena of the positive or negative impacts of the Affordable Care Act, and I still, today, don't ever want to touch it on siding with what are the benefits and what are the downfalls of it.

But I think what Emily is talking about is something that we might actually want or need to consider as the Commission, and it's not about the imperatives of the program. Thou shalt do. We're not going to get into that or making policy recommendations on that, but what we're going to see -- and we've just had this one small sliver of the program -- how it

will impact home health care delivery in the state. I believe the Commission has some responsibility on helping craft, how do we deal with the impact of changes in services that might result from the Affordable Care Act, and how will we help influence the provision of care throughout the state?

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So I think that's within our purview, and I think it's something -- the updates help, but eventually, we're going to get to making some decision points on what might be the most prudent policy approach to providing care across the state.

So again, not the political side; I truly don't want to touch that. You got that job.

COMMISSIONER DAVIDSON: So Deb, the other part of it is that, I remember last year, we had a conversation, and I expressed concern many times, about dealing with the cost and not talking about the value of what it is that we're getting for what we're paying. And I remember vividly being assured last year that, well, this year, we were going to focus on cost — this was last year — but next year — which is now — we were really going to start getting into the value and how Alaska benefits from these expenditures. And so I'm looking at the schedule and trying to figure out when that's happening. Is this meeting the quality meeting and the benefit meeting or is that happening later? So far, it's — yeah. But that was our theme last year, and this year was going to be — we were going to talk more about value and the

benefit that Alaskans receive from what we are spending on health care.

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COMMISSIONER ERICKSON: Well, this reflects the agenda that the Commission approved at the end of last calendar year. So maybe we were not understanding, when we talked about value, what exactly that meant. So we maybe need to be more specific when we talk about if we want to study the benefits of the health care system. I'm not recalling that being part of the conversation that what we were going to was to study the benefits of the health system, but that we were going to bring in the value equation when we talk about costs, which involves quality. And so did have a slide -- and I don't think we have it again this time -- that looked at, at a very general level, more of the quality metrics in the health care system.

COMMISSIONER DAVIDSON: There wasn't any confusion on my part, so I'll be clear about that. I -- we -- I remember very vividly talking about, when all the reports were done, very concerned that the message we were sending to the public is, look at the huge cost, but we're not showing the opposite side of that, which is what is the benefit that we're getting, and we really needed to be focused on value.

And the analogy I used at the time was that, you know, who would have thought that, today, people would pay \$1,000 for a flat screen TV, but people are buying flat screen TVs,

not because they cost \$1,000, but they want them because, for that person, that has value. And so we can talk about costs, but what is that people are getting for what we're paying? It isn't that they're paying -- people don't feel like they're paying too much. People feel like they're not getting value for what it is that we're paying. And so how are we -- so far, all we've done is talk about cost. We're only presenting half of the equation. We're only presenting half of the issue. So when does that happen because I don't -- I mean, you're saying you're going to talk about and you described it, but I can't see that here, and I just want to make sure that we're not falling into the same trap we fell into last year.

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COMMISSIONER ERICKSON: Well, I think we need to get much more specific then about how -- what exactly is the question about benefits that you think the Commission should be answering?

about -- we talked -- well, I guess two years ago. I guess a year-and-a-half ago, we were talking about value, the value of what we're getting for what we're paying in the health care delivery system, and there was concern about -- I know I expressed it, and a couple of others did as well -- the report was so much based upon the cost, but there wasn't the balanced perspective of, by the way, this is what we're getting. It's like telling somebody you paid, you know, \$40,000 for a car.

Well, what did you get for that car? Did you get a jalopy?

Did you get a Flintstones pedal car or did you get a -
whatever the -- I don't have one of those kinds of cars. So

did you get the fanciest car that can also do all of these

other great things? But where does that -- do you remember

that conversation, Pat?

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examples of where you might be heading, and I do remember the conversation. We rarely touch on quality metrics here and that's -- you know, it's not the tested and tried and true approach. It doesn't always equal higher quality, if you can demonstrate that you've got a lower mortality rate for CHF, congestive heart failure, patients, but these are the indicators we've got. And it's clear we have high costs in health care in the state of Alaska, but perhaps -- and one example in which we've achieved huge grounds -- went from almost the worst to nearly the best in the nation -- is in neonatal mortality. We've spent a lot of dollars to turn that around, to improve that condition, and this is part of the value equation.

For those parents, they'll never know that they've avoided a neonatal death, but we know it statistically. There is real value in telling that to our public as well, alongside the cost associated with care. So it does start to balance out the equation, and I think we could, and should, start to

look at those pieces of information that are part of the data. They're part of the claims data, but they're also a separate one in which we're reporting nationally, the National Safety Measures and Goals. There's a story to be told, and I think - and I hope that's what you were aiming at, telling the whole story.

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COMMISSIONER HARRELL: You know, I'm the newer member to the Commission, but I had couched your concern. Looking at the agenda, the June meeting and this meeting, I had framed, in my mind, really as sort of quality access is sort of a surrogate, in my mind, to quality and then today's focus and tomorrow's focus is about quality coned down to a particular issue. So I think you get to value. If we reframe it in terms of the equation, value is quality divided by cost. You actually do get to that. It becomes a language issue in terms of how you begin to convey that, but I think the June meeting and this meeting really are about quality, and the cost meeting is the denominator and that is the equation that this Body decided on before I got here, that we were going to represent value. Is that -- does reframing it help in terms of where you're at in struggling?

COMMISSIONER DAVIDSON: Sort of.

COMMISSIONER ERICKSON: Or does coming up with a specific set of metrics because that's what we're trying to move towards, that I had hoped to do this year that we're not going

to do, but I think, in conjunction with Healthy Alaskans 2020,
we can. So we're this is the slide I was remembering from
before, looking at value in terms of the four aspects of our
goal, our goal being access. And if we look at health
insurance coverage is one aspect of access depending on
what measurement, whether you include IHS beneficiaries or not
in the covered population between 14% and 19% of our
population is uninsured that our per capita spending in
terms of cost is the second highest in the nation behind
Massachusetts, and there are a number of different
organizations that do kind of an aggregate metric on quality,
quality of health care. And this wouldn't specifically
it's 2010 data from the U.S. Department of Health and Human
Services, Health Research and Quality the State dashboard
on health care quality. And in 2010, we're ranked 38th. I
know the 2011 data just came out, and the dial on the
dashboard for Alaska actually went down. I don't know if that
moved us in terms of national ranking and then in terms of the
United Health Foundation's rankings on health status, which
isn't a pure ranking. I think they pull in some health
quality and access metrics into that as well. We're ranked
35th.

So this was just a real high level cut at looking more at value and what we're getting for the cost. So if you want to have more of a conversation on value, I think it would help me

if you could define a little more specifically what are the quality metrics that we should be looking.

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COMMISSIONER BRANCO: This -- I think we're on a three-legged stool here. This is public health data, hospital cost data, but we're not looking at the health outcomes of the patient populations we're serving as the third leg of that stool, and there are lots of data sources that we could begin to gather and consider amongst ourselves.

Hospitalcompare.com is one of those sites where there are common metrics across the nation in which we can begin to rank ourselves on how are we performing, age caps, scores, and the outpatient of age caps. These are all pieces of the puzzle that will start to add some real meaning to the value word, itself, not just simply improving the management of our diabetes population, but actually looking at health outcomes where we're determining the number of patients in our communities who have a Hemoglobin Alc below seven. It will actually mean something if we put cost -- if the health care communities are putting cost towards lowering that or raising the number of people who are below that threshold, there is value.

So going along that line is how I would round this out even further, looking at commonly available data sources that are already -- hospitals are throwing them in. Primary care providers are throwing them as well.

COMMISSIONER ERICKSON: Yes, Dr. Urata?

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COMMISSIONER URATA: As I recall, we had a Mission

Statement last time I was here. That actually was my first

time. And among those was that we were going to measure

ourselves by some sort of metric, and I think maybe this

should be part of that exercise is to develop what we're going

to actually measure to see if we could change, you know, to

see if we've covered our mission. Oh, we actually put down

some metrics.

COMMISSIONER ERICKSON: We did, at the very highest level and talked about how we needed -- we would, over the next year, get into the next level of detail. So some additional metrics that will.....

COMMISSIONER URATA: Support those.

COMMISSIONER ERICKSON:support those, right.

COMMISSIONER URATA: Yeah. And perhaps that's where we should be going per what Valerie says. Does that give you detail enough?

COMMISSIONER ERICKSON: No. So what we need is to identify then, for our 2013 agenda, what, more specifically, do you want to do around these metrics? Do you want to just compile and study together the quality metrics that are already available through some of these other national sites or do you want to do something -- to what end do you want to -- do you want us to publish our own report on the quality

metrics?

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COMMISSIONER BRANCO: I actually want to influence behavior to make these numbers and equations turn into actual action that will benefit the population of Alaska. So looking at raw numbers does nothing. We can look at those all day.

COMMISSIONER KELLER: I'm just confused. I think Val said she wanted to advocate, emphasis the success, and to me, I don't get that compared to what you're saying, which is let's evaluate what we're doing so that we can have a measure to see, you know, where we're at specifically and be able to look back later on to see where -- and I see that as two different issues completely. And I went back and read the Mission Statement, too, after we started this discussion, and our role, as I see it, is to transform health care up here because it needs transforming. And so we either document why it needs transforming, you know, or some other strategy, and I think we've done a really good job moving down the road picking the low-hanging fruit that we see that should be addressed, and you know, I think it's kind of late in the game to try to reset that whole thing up, and you know, that's kind of what I hear.

COMMISSIONER DAVIDSON: I was -- I thought we were going to -- by transforming our health care delivery system, I think that requires a balanced approach, which is what Pat was talking about, and he articulated it a lot better than I did.

But if we present yet another Health Care Commission Report that only talks about cost, that is one small part of our health care -- of shining a light on the health care delivery system. It is not a balanced perspective. And I guess I should just saw what Pat said. I want to make sure that, when the report comes out and we're doing our work, it is a balanced perspective. It isn't all just about cost because we're getting something for that cost, and what is that we're getting? What's the value of what we're getting.

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CHAIR HURLBURT: You know, Val, are you measuring -doing HEDIS measurements in the tribal health system now, do
you know that? Are those kinds of measurements, which would
include things like neonatal mortality? It would include how
are you doing as far as getting a low level Hemoglobin Alc.
It would include how you're doing in immunization rates,
include how you're doing in mammogram rates. There is whole
list of things. Is that the kind of thing that you have in
mind?

COMMISSIONER DAVIDSON: It's what Pat said. It's providing a balanced perspective. It's not just talking about the cost. It's the whole thing. If you're going to be providing a snapshot of here's where we are, then don't just talk about money.

CHAIR HURLBURT: But you're asking, what are some outcomes, what are getting for the money? And HEDIS

measurements are designed to be quality measures. You're spending this money. What are we getting for it? And that's why I'm asking if you see that as the kind of thing you're getting at because, to get at it, we have to get something specific to measure.

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System in a snapshot, you know, and we have this cost, what we get for our cost is not very good. And so I think what we're trying to do is see if we can get better so the cost gives us more value. And maybe that's where we're having discomfort understanding what the benefits are because, from my perspective and why I joined this Commission, you know, I don't think we're getting a whole lot of value right now, but of course, I hear some stories and some of it's good, but I think we have to do better.

COMMISSIONER ENNIS: I wonder if we're needing to look -or Val, what you're talking is an example, like the increased
expansion of medical services in the rural areas that have
great benefit. Yes; our costs are high when compared to other
states, significantly higher. But a good example of where the
value lies is in the fact that people can get medical care in
their home, rural home communities rather than being Medivac'd
or coming in, in expensive airplanes. So could that be an
example of value for the increased dollar?

COMMISSIONER DAVIDSON: And I quess -- and let me put it

1	to you in as basic of terms as I can possibly imagine. I
2	think the fact that, yes, where we are now is at a different
3	place than where we were in my mother's generation. I am
4	thrilled that my children do not have a 44% survival rate. I
5	mean, my mom there were nine kids in her family; four of
6	them lived simply because we didn't have medical care. They
7	didn't have immunizations. They didn't have any of that.
8	Five siblings died; four lived. And so yes; the Alaska health
9	care delivery system costs more. You know, obviously, it
10	does, but we keep talking about cost. Where do we present the
11	other balanced perspective of, yes, here's where we are now in
12	terms of cost, but here's where we also are now in terms of
13	benefit? And whatever those measures are, if those if,
14	medically, those are done through HEDIS measures, if they're
15	done through infant mortality, fine; pick some. But the fact
16	that our children are not more likely to die now than they are
17	to live is a really thing in Alaska, and in many parts of our
18	state, that was not possible before, but we don't document
19	that. We don't talk about that. It doesn't appear in our
20	reports. We don't it's all about cost. Look at how much
21	it costs in Alaska, but there is also great benefit, and where
22	do we capture that?

CHAIR HURLBURT: So -- but our data has to be population-based. You gave the story of your mother. I can give stories similar, heart-wrenching stories from when I first came here,

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but to base it on the population, then you talk about infant mortality rates, post-neonatal infant mortality, average life expectancy. You talk about proxies. I mentioned Hemoglobin Alc. You really don't care. Who cares what Hemoglobin Alc is? What you care about is, are you controlling diabetes, so you don't have amputations and blindness and kidney failure and those things? But we aren't able to measure that in a reasonable timeframe, but we believe, in a reasonable timeframe, if we can manage the diabetics, who, if the Hemoglobin Alc is good, you're more apt to retain those. We can do those on a population basis, but I would say, to pick your mom, a 44% survival rate, then we need to base that on a population, but that's infant mortality rates; that's neonatal infant mortality rates.

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To say if more services in the Bush is a good thing, that's not really an outcome. Now take the dental health aides. Who cares if there is a dental health aide in the village or not? What you care about is, are kids keeping their teeth? Are they not having a bunch of cavities? Are they not losing those? So that's what you want to measure. And then we think we have a way of getting to that, but isn't that the success? Isn't that the outcome?

COMMISSIONER DAVIDSON: So how do we document that, so that -- I mean, I can't tell you how many people who I have had conversations with who are traditional people, who have

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read previous reports that said, so the Health Care Commission is all about money. It's about how much health care costs.

So what I'm asking for is, where is the balanced perspective of what is it that we get? And measure infant -- whatever it is. Pick something, but it shouldn't just be about cost, and so far, that's what our last report was, it was about money.

COMMISSIONER URATA: I have a thought that may be helpful. How about if we go back in time and check infant mortality in the '40s, '50s, '60s to show the -- I'm pretty sure it's gone up -- improvement -- or excuse me, going down. Yeah. There was a little slip there. So that it's improving, as well as maybe some other data that we have in the past to show where we were and where we are now. And I don't if you have costs that would be pertinent to health care, you know, spending in the '40s, '50s, and '60s, '70s. And then that would perhaps give the perspective that you're looking for.

COMMISSIONER ERICKSON: Except, how much of those health improvements were due to public health improvements in the community and sanitation systems as opposed to the medical care system?

COMMISSIONER URATA: You know, it may not be accurate to that level of rigor that you might be asking, but it might be a good snapshot of what we're looking for, you know....

COMMISSIONER ERICKSON: Right. Right. Well, you know, I mean, the concern....

COMMISSIONER URATA:a perspective.

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COMMISSIONER ERICKSON: And I'm not arguing with putting outcomes in. We'll put outcomes in our next report. But we've been focused on cost because our concern is -- it's not that we don't value -- and I think, you know, it's unfortunate that our studies of the cost and pricing in the health care system have been viewed by some as trying to demonize the health care industry because that was not the intent, but if it looks bad, it's because it is bad. And our concern is affordability.

And my concern is we do value the health care services that our health care provider organizations and our health care clinicians provide, and it is becoming increasingly unaffordable.

More and more small businesses are dropping insurance coverage, and the Medicaid program, regardless of what happens with the expansion program, is -- because it's squeezing out other services and core functions of government with things that are going to be happening with both the state budget and with the federal budget over the next few years, it's those most vulnerable people that are served by the Medicare and Medicaid programs who are going to suffer. If we don't figure out a way to make the system more -- the services in the system and the system, itself, more affordable both for government, since government, in this state, pays 60% of all

of the health care dollars, and for employers and for individuals who are buying insurance for their employees and for their families. And so that's why we've been focused on cost initially because we were trying to understand why prices were so much higher here. Yes?

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COMMISSIONER BRANCO: I'm not feeling especially persecuted -- no. Just teasing. That was just dramatics. When we look at the value equation -- and we did monumental work in analyzing the costs of health care in the state of Alaska -- we can definitely change the value by reducing costs. We can ignore quality and still improve the value equation. It's arithmetic. It's simple, straightforward.

I think it's time to evolve more and get more value by also addressing the quality issue. Don't drop our focus on reducing cost. Let's make sure what we're doing doesn't have a negative impact on quality. So I think that's what Emily started to tee up with. What is the impact going to be from the Affordable Care Act? How are we going to respond within our communities and statewide, and how are we going to measure the preservation of the quality while we're facing significantly reduced reimbursement and higher demands on reducing overall costs? I think we have to add in the positive pieces as well and begin to measure those, so that's where I'm at.

COMMISSIONER ERICKSON: Well -- and I mean, I really

thought that's what we were doing this year, too, by -- back to Colonel Harrell's comment, we understand better, after last year's study on costs, some of the issues that are driving higher prices here, but instead of coming back this year and coming up with cost control strategies and recommending some sort of rate commission be established to control prices, we're focused on how can we improve access through continued enhancement and development and use of telecommunications technologies that actually save money in the overall system and improve quality and access to care?

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We had picked End-of-Life Care as a particular issue because it's a particularly costly time and a time when, we found in our earlier research, that quality of care from the patients' and families' perspective, especially, was horrible in many cases. So this was an area where we could improve quality of care for patients and their families, and at the same time, make the overall system more affordable.

And then the issue we're studying the fall, the employer's role, this was an area where we had learned that the evolution and the development -- now rapid evolution and development of employee health management programs is an area where employers are implementing some successful strategies, both in improving the health of their workforce through employee -- or worksite wellness programs and redesigning their benefit programs, so that they're more focused on

outcomes, improved patient outcomes, in addition to also containing the cost growth.

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So that's why I thought we were focused on the value equation this year. And maybe we're talking and not communicating, but one of the other things that I did, with Colleen's help -- thank you, Colleen. I had been capturing our specific votes that we've made over the past couple of And so behind tab three, one of the documents behind tab three is we have just a cleaned up, final version of our voting records, all of our voting records since we were conceived and born, and we will continue doing that. So when we have -- everything that we may have had an official vote on. So if we're not doing something that you think we agreed to do or we're not doing it right or well or whatever, we need to revisit it, and maybe we can make some clear motions and take votes on specific activity so it's more clear exactly what we're going to do and we have it captured in an actual voting record.

COMMISSIONER BRANCO: I think you stated it well. The conversation we had on access -- in particular, one narrow area the telemedicine -- that really -- while it's not quantifiable yet -- we don't exactly know what we're measuring and what we're achieving -- we certainly know in our guts that that outreach really has a powerful impact and is going to improve the care to all of our outlying communities, in

particular, in so many areas of specialties they could not and would not be able to go face-to-face to those communities.

While it's not -- we don't have a 57% quality improvement in telehealth, it's certainly one that we can state out loud that there is an improvement and there are initiatives to improve that quality.

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COMMISSIONER ERICKSON: (Indiscernible - away from mic) been waiting and then Emily.

COMMISSIONER DAVIS: Thank you. So I've been listening, not talking, to try to understand, and I don't know, for some reason, it reminds me of something my dad used to say. He was an English teacher, and he'd say, I think you put the wrong emphasis on the right syllable. But I think this is just a matter of emphasis, is what I'm hearing. I don't really hear any disagreement. I really don't. I just hear a matter of emphasis and a matter of timing -- there is just a lot -- and maybe a different perspective. And so maybe what we can agree to is that it would be really interesting and helpful to try to look at the view that Val and Pat are putting out, which is -- and I was thinking the same thing that Bob said, that maybe a historical perspective would just be a really good thing to document there, and there are some books that have, you know, talked about the way things were in the past in Colonial Days -- not Colonial Days, but the homestead days, Dust Bowl Days, you know, when people were being brought. And I think that

1	would be interesting and then move into and look at the HEDIS
2	measures. I mean, I think there are some well-established
3	measures. But we're just struggling to know kind of what that
4	data set is, but I think finer minds could figure that out and
5	come back and say, here's what we think we want to look at and
6	then let's have a session and look at those. Let's, you know,
7	have some history and have over time measures that we look at
8	and then have some current measures, the HEDIS measures or
9	whatever the best set is, that we use to compare ourselves,
10	you know, to others. And you know, I think that does start to
11	get at the value or to look at the things that have that
12	have been the outcomes, and it is a mixed bag, and it is going
13	to include some things that aren't medicine, that are public
14	health, what are vaccinations, you know, those sorts of
15	things, and I think that's okay because the question is, so
16	we're doing all this, what do we get for it in terms of
17	health? And that's, I think, worth doing, and I haven't heard
18	anyone disagree with Val's suggestion that we do that. It's
19	just when and how and what the specifics are. Thanks.
20	COMMISSIONER ENNIS: I wanted to follow-up on
21	COMMISSIONER ERICKSON: Emily had her hand up for a
22	while.

COMMISSIONER ENNIS:Pat's comment a little while ago as we were talking about the Supreme Court decision and the potential impact, negative impact on services and whether

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we have the responsibility to take a look at that.

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My concern is that there is a November timeline, which would mean that, should we want to review any of this information, we would need to do that at our next meeting.

COMMISSIONER ERICKSON: I wanted to clarify that the November deadline is for the State to decide whether -- how they want to partner with the federal government on the Insurance Exchange. So again, I don't know that -- there is not going to be a policy decision about whether there should be a consumer assistance program in Insurance Exchange. It's whether the State is going to do the Consumer Assistance Program or whether the federal government is going to do it, related to the Exchange specifically. The Governor has decided that the federal government will do the Insurance Exchange. So we have nothing, really, to add to that discussion. And then whether the -- I think it's whether the insurance oversight will be done by the federal government or the State is the other variable. So it's not a what; it's a who and how.

COMMISSIONER ENNIS: And whether or not -- thank you -- we have any need to review that decision as a Commission is my question in relation to impact.

COMMISSIONER KELLER: Yeah. If I could, I'm just reflecting a little bit. From my perspective, cost -- even though we get tired of talking about it, that is the issue,

1	you know. Either this thing is going the one thing I think
2	just I hate to repeat the obvious, you know, for all of
3	us, but when we say this thing is not sustainable, that means
4	there are going to be big changes down the road, no matter
5	what, and our role, as I see it, is that we try to steer those
6	changes, you know. You know, if we do nothing, it really
7	crashes. None of us really expect, you know. And we are the
8	vehicle, I think, to get this thing down the road, and I just
9	can't see how we can avoid focusing on the cost. I don't
10	know. You know, I mean, I know that that's a little out of
11	context and a little bit from 100,000 foot level and a little
12	bit thrown in here, but I'm just sitting here thinking that,
13	that, you know, we really have to come up with solutions. And
14	from perspective as the guy that's sitting in the Legislature
15	that's going to have to deal with the money end here
16	eventually, you know, in this budget setting and in this cost
17	increase that we're seeing, you know, I'm just encouraging
18	you, as my respected friends, to really press on in coming up
19	with some solutions for us. Thanks.
20	COMMISSIONER DAVIS: Deb, I'm just wondering if some the

questions that Emily has raised won't be addressed by Commissioner Streur tomorrow and perhaps that would be a good time to ask questions, find out what are decisions and what are "who and how and when."

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CHAIR HURLBURT: I think Dr. Ritchie mentioned evidence-

based medicine. We've talked about it some in the past. We haven't explored it a lot, but I think greater use of high grade evidence and coverage in clinical decision-making clearly enhances the value equation that we have.

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For example, I assume Providence Hospital is probably like any other high quality, large community hospital in the country, and if the 30% of the stents that they put in coronary arteries for chronic stable angina, if they stop doing it, nobody would be harmed. There would be a lot of money saved. It would greatly enhance the value equation for what's being spent on an incredibly wonderful, new medical intervention, but that, in substantial numbers, is being inappropriately used here and everywhere else. Yeah?

COMMISSIONER BRANCO: I have a -- there is one cost savings measure known to every hospital administrator and that's a tight formulary, and it's evidence-based medicine. If you limited your formulary to evidence-based medicine instead of the more esoteric versions that are high cost -- but that's one of those tough decisions that we're going to have to make and introduce to our communities, that narrowing the scope of what we offer will actually improve care and reduce costs.

COMMISSIONER STINSON: For those of you who remember about two years ago, and I still feel this way, it is absolutely the future of medicine. When Commissioner Streur

says, I spend a billion dollars a year, I don't know what I'm getting, I don't know who is getting better, and I don't know if we're even using the money wisely, that's pretty sad, and we have got to go that way. And I already talked about how we're working on a little bit of telemedicine. We are also -- when the group comes up from the University of Washington, we're going to be setting up evidence-based medicine at our clinics.

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COMMISSIONER CAMPBELL: Well, I was just going to remind everybody that, in January of '11, we did pass a motion to add evidence-based medicine to our recommendations, and I just -- we need to follow-up and see where that's going. But Pat's right. The tight formulary is the way to save a couple of bucks.

COMMISSIONER URATA: Can somebody give me an example of how to get evidence-based medicine at the bedside? Now what I think I'm doing, when I say evidence-based medicine, is I open this up and I go on my Safari and then I go to UpToDate, and UpToDate has -- you look up, under UpToDate, the diagnosis and then it tells you what is -- you know, I'm told up-to-date information on how to do diabetes or a heart attack or a stroke or something acute.

So is that what you guys mean by evidence-based medicine?

I mean, it's based on studies, scientific studies, double
blinded studies on how to treat a certain thing, but not

everything is covered in evidence-based medicine.

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So you know, it's a catch word that I see that can't be applied to absolutely everything that we see everyday in a clinic or a hospital setting. So you know, it kind of -- I know it's important, but it's not the answer to everything.

CHAIR HURLBURT: I would say, clearly, there is not evidence, and in a lot of ways, it's more challenging for the provider than it is for the payer. The payer has more -- in a relaxed way, can look at what are coverage decisions and what are authorization decisions and use tools that are available, like Hayes, like Cochrane, like a number of other tools. same kind of thinking, I think, needs to inform what the clinician does, but that's -- it cannot just be the payer's doing that because every patient is going to be different. But there are tools that are available. There is clear evidence that the transcutaneous procedure for injecting stuff into the in distal space doesn't do good. As an informed physician, your role, much more than when I first started practice, is as an educator of your patient and then you make joint decisions. It's not just you come from on high, but it's a joint decision. But I think, in much of what you do, there is evidence, and there are training opportunities that physicians have.

When I read my American College of Surgeons Journal, month-by-month, there is a section in there every month now on

1 evidence-based analyses. So you're right. It doesn't inform 2 everything that you do. I think some of it can be enhanced by electronic health records systems. Some of it's probably 3 4 enhanced by the partnership with other provider groups, like 5 pharmacists, as they partner with us and enhance the quality 6 of care. But absolutely, it's not easy and it's sure not 7 100%. But conceptually, I think physicians need to use it. We need to understand that expert opinion and consensus 8 conferences are not worth a whole lot, but -- and then some 9 10 things you can do double-blinded, randomized control trials 11 for and a whole lot of things you just flat can't. Yeah? 12 COMMISSIONER BRANCO: Do you guys remember the two-inch 13 thick book, Current Therapy, published every two years? That 14 was evidence-based medicine from my era. It's a little more

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up-to-date now.

COMMISSIONER ERICKSON: That's okay. David was next.

COMMISSIONER MORGAN: It's probably kind of late. I was just going to say that community health centers, in their UBS report, basically reports outcomes of basically the questions that everyone is sort of -- though they're a minority group of service providers, they basically detail out who they delivered services to and how much they delivered and then certain standards they're supposed to meet by delivering them. You could -- quality measures, that kind of stuff. And then I was thinking about meaningful use measures that we're having

to do. That's another area that could be compiled.

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But when you start getting into this kind of stuff, I mean, I just think we've outlined, just in the last 45 minutes, a good eight months of work. I mean, I don't know if you can squish all this in to come up with what we're talking about. I think you can come up with some measures and kind of track some stuff of how it's turning out, but it's not an easy thing. That's okay, but it's going to be a bunch of stuff, and I think we're going to have to pull a list together and then go through it. And then there's always -- and then we'll start getting into marginally utility.

My friend -- in fact, he filled this seat -- used to scream at me about widgets, but then you get to the point, eventually, that so many dollars in, so much quality and so much outcomes out, and then you can -- and I hope no one screams widgets, but then you can say, well, you know, spending this money will only produce this much, when you could spend more of this money and you get -- you know what I'm getting at here. And I think that's what we're kind of trying to get to, and if we actually pull it off, it would -- Nobel Prizes in -- or economics anyway to everybody, I think. But that's just a comment. It didn't help, but hey, it used up four minutes, as we get close to the 4 o'clock.

COMMISSIONER ERICKSON: This is still just kind of a random thought, but our conversation around the All-Payer

Claims Database -- part of the reason the Commission initially had recommended it before the public comment period, and then based on the public comment, just decided to study it some more was followed from a similar conversation that we didn't have a commonly used data set available in the state for measuring quality of health care services, and this was going to be one tool -- could be one tool for supporting that and would be kind of systems-based kind of foundation-building piece that the Commission could recommend as an improvement to the health care system that could benefit lots of aspects related to quality, providing data for individual clinicians to work on quality improvement measures, providing some systemwide, statewide quality measures for reporting purposes, providing quality reports for the public. So that's why we're studying that one particular solution, was to provide a foundation to support continued and expanded quality measurement and discussions.

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If it would be helpful, I could go pull the most recent report from the Agency for Health Care Research and Quality on the State Health Care Quality Measures, and there are over 100 different quality measures that they roll up and then give a score, and it shows on a dashboard, and the 2011 report card just came out -- or dashboard just came out, and I could pull that and bring it tomorrow morning, a copy for everybody to look at, if that would be helpful.

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And I have, because of this conversation in the past, provided copies, and I think you have the most recent one. It would be -- well, maybe you don't have the most recent one.

Each year, the Division of Public Health provides a report on their, I think, 30-35 key health indicators. So as a population health outcomes measure, I've provided those to you in the past and had also included, so behavioral wouldn't be left out -- the Alaska Mental Health Trust Authority, in partnership with the Department, put out just kind of a one-page or a two-page report card each year on population health measures related to behavioral health.

COMMISSIONER URATA: (Indiscernible - away from mic)

COMMISSIONER ERICKSON: That dashboard on behavioral

health, I do not believe does; however, the Division of Public

Health's report for each of the key outcome measures includes

a ten-year trend graph and also measures against the Healthy

Alaskans 2010 benchmark and also provides a U.S. ten-year

trend line comparison.

COMMISSIONER KELLER: (Indiscernible - away from mic)

COMMISSIONER ERICKSON: It doesn't go back 50 years, but we have somebody in our Information Technology Section....

COMMISSIONER KELLER: Ward and I go back 50 years.

COMMISSIONER ERICKSON: I know you do. I don't dare -so have you been around long enough? Dr. Hurlburt, do you
remember the *Perrin* (ph) *Report*? I think I was, like, the

1	only one left in the State with a copy of the Perrin Report,
2	and some IT techs have been turning it into a PDF for me.
3	It's a report that the federal government did on health status
4	of Alaskans in 1950. So I mean, we do we have that
5	historical
6	COMMISSIONER DAVIS: (Indiscernible - away from mic)
7	COMMISSIONER ERICKSON: You could tell us what health
8	care premiums were in 1950, too? So we can pull we'll pull
9	the historical information together, and we'll have the health
10	outcomes. If it would so Val, do you think it would help,
11	if we pulled those pieces we provided, but hadn't spent a lot
12	of time studying together, but I could pull summaries of all
13	of those into our 2012 report.
14	COMMISSIONER URATA: Excuse me. Do you have the
15	longevity or expected life life expectancy data as well,
16	too?
17	COMMISSIONER ERICKSON: It's been a long day. Yes. Yes.
18	COMMISSIONER BRANCO: And I heard Keith can fill in all
19	the dots for the 40 years prior to
20	COMMISSIONER KELLER: Your formulary if you'll indulge
21	me story a true story. When I was I hadn't been an
22	Administrator very long, and we had a medical staff meeting
23	one day, and a couple of docs came in and wanted to make sure
24	that the pharmacy stocked "X" from Pfizer. And another doc
25	down the table said, oh, detail man has been in. Called your

down the table said, oh, detail man has been in. Called your

1	broker yet? You know, to buy Pilzer. And that used to
2	happen. That's why your formulary got expanded.
3	(Pause)
4	COMMISSIONER BRANCO: A motion to adjourn.
5	COMMISSIONER ERICKSON: How about a friendly amendment,
6	motion to recess?
7	COMMISSIONER BRANCO: Certainly.
8	COMMISSIONER ERICKSON: What I'm going to do is bring
9	some of those reports for you all tomorrow morning. We can
10	continue this conversation, but also take a look at, in your
11	PowerPoint, those slides on kind of key findings about
12	malpractice and telehealth and behavioral health, and if we
13	have time in the morning, we'll visit those. And again, it is
14	it was one of the extra handouts you got this morning in
15	your packet, and it's a set of PowerPoint slides, Alaska
16	Health Care Commission Meeting Discussion Guide. It looks
17	like this. Do you think it's okay if they leave their
18	notebooks?
19	UNIDENTIFIED FEMALE: I'm locking this right now.
20	COMMISSIONER ERICKSON: Oh, we can lock it? Good. Thank
21	you. Yes. Security will lock the doors. Thank you.
22	4 : 05
23	(Off record)
24	SESSION RECESSED

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